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Unpaid caregiving and sleep disturbance in mid- and later life in England

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Unpaid caregiving and sleep disturbance in mid- and later life in England

Emma Maun

2022

SUBMITTED FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

INSTITUTE OF GERONTOLOGY

DEPARTMENT OF GLOBAL HEALTH AND SOCIAL MEDICINE

KING'S COLLEGE LONDON

Statement of authorship

I, Emma Maun, declare this thesis and the work presented in it are my own and have been generated by me as the result of my own original research.

I confirm that:

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Title of the thesis:

Unpaid caregiving and sleep disturbance in mid- and later life in England.

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Acronyms

ADL	Activity of daily living
ANOVA	Analysis of variance
CES-D	Center for Epidemiologic Studies depression scale
CI	Confidence interval
COVID-19	Coronavirus disease
ELSA	English Longitudinal Study of Ageing
FE	Fixed effects
HRS	Health and Retirement Survey
ICC	Intraclass correlation coefficient
JSS	Jenkins sleep scale
LA	Local Authority
LPM	Linear probability model
MAR	Missing at random
MCAR	Missing completely at random
OR	Odds ratio
PSQI	Pittsburgh Sleep Quality Index
RE	Random effects
RR	Relative risk ratio
SRH	Self-rated health
SHARE	Survey for Health, Ageing and Retirement in Europe
WBRE	Within-between random effects

Abstract

Unpaid caregivers provide most of the support for individuals with social care needs in England and maintaining caregiver health and wellbeing is important to sustaining their role. Sleep disturbance has been linked to poorer health and lower quality of life, and, among caregivers, may be a reason for ceasing care. However, our understanding of caregiver sleep from longitudinal and population-based studies is limited. This thesis investigated relationships between caregiving and sleep disturbance among women and men aged fifty and over in England. It was guided by the stress process framework and insights from the sociology of sleep. The conceptual framework for the study focused on characteristics of caregiving and periods of transition and stability likely to be stressful, as well as the influence of gendered social roles, and changes in partner health among couples. The research aimed to identify, first, how care hours and relationship to the care recipient were associated with sleep disturbance; second, differences in patterns of sleep disturbance across a care episode and by care duration, and third, associations with co-resident care and partner health in the context of cohabiting couples. Fixed effect models were the main statistical approach used to analyse change within individuals, on data drawn primarily from Waves 4, 6 and 8 of the English Longitudinal Study of Ageing (ELSA). Wave 1 of the ELSA COVID-19 sub-study was also analysed, during a period likely to exacerbate stressors for some caregivers. Results indicated limited associations between some aspects of unpaid care, partner health and sleep disturbance. Spouse care and care of 20 or more hours per week were linked to small increases in the probability of sleep disturbance among men. Among women, sleep disturbance was related to care durations of two or more waves, and unexpectedly, ceasing care, while depressive symptoms accounted for associations in some analyses. Among couples, no association was found with co-resident care, but several partner health conditions were linked to sleep disturbance among women. As expected, changes in individual health were strongly associated with sleep disturbance. Limited evidence supported hypothesised sleep disturbance linked to caregiving, however, sleep disturbance may be more transient than could be measured by the data available. Future research would benefit from availability of more frequently measured sleep data enabling closer modelling of changing circumstances and sleep.

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Chapter one - Introduction

This chapter briefly outlines the rationale for the research carried out in this thesis in section 1.1, and its aims and objectives in section 1.2. It sets out the structure of the document, section 1.3.

1.1 RATIONALE FOR THE RESEARCH

Approximately six million people, or 12% of the population aged over 16, identified as an unpaid caregiver in the Census 2011 (Office for National Statistics, 2017); providing crucial support to family and friends to live safely and well. More recent estimates indicate 17% of the adult population provided unpaid help or support in 2019 (Ashford & Hill, 2020), rising to 48% of adults providing help to someone outside their household during the early months of the COVID-19 pandemic (Office for National Statistics, 2020a). Despite considerable demand for social care, in 2016/7, there were only 1.5 million paid care employees (Humphries, Thorlby, Holder, Hall, & Charles, 2016). Unpaid caregiving is therefore a vital part of social care in England. Projections indicate rising future need for unpaid care, driven by population ageing, social and health trends (Agree & Glaser, 2009; Brimblecombe, Fernandez, Knapp, Rehill, & Wittenberg, 2018; Pickard, 2015). Moreover, the number of older adults receiving state-funded social care decreased by 26% between 2009/10 and 2017/18, following central Government grant cuts, rising service costs and other challenges (Crawford, Stoye, & Zaranko, 2021; Glasby, Zhang, Bennett, & Hall, 2021). Lack of integration with health services and other strains on the social care system have been exacerbated by the COVID-19 pandemic (Mahase, 2021). The Care Act 2014 marked an increased legislative recognition of the contribution of unpaid caregivers, enshrining a Local Authority duty to assess caregiver needs, with a focus on wellbeing (Care Act, 2014). Practical implementation of the Act has been slow, hampered by uncertain adult social care finances and the other systemic problems (Fernandez et al., 2020). Nevertheless, maintaining caregiver health and wellbeing is acknowledged as important for individual caregivers and their ability and

willingness to sustain the care they provide (Department of Health and Social Care, 2021).

While some studies have found caregiving to be neutral or associated with benefits for health (Bom & Stöckel, 2021; Rafnsson, Shankar, & Steptoe, 2017), spouse care and longer hours of care have often been associated with poorer mental health, greater caregiver burden¹ and lower quality of life (Chappell, Dujela, & Smith, 2015; Kaschowitz & Brandt, 2017; Sacco, König, Westerlund, & Platts, 2022). One possible contributor to poorer caregiver health may be through sleep disturbances linked to care provision (Pinquart & Soerensen, 2007). Sleep is increasingly recognised as important for health and wellbeing (Fung, Vitiello, Alessi, Kuchel, & the AGS/NIA Sleep Conference Planning Committee, and Faculty, 2016). There is strong evidence linking disturbed (as well as short) sleep to cardiovascular and cardiometabolic health: hypertension, obesity, diabetes, and heart conditions (Cappuccio & Miller, 2018). Sleep disturbance may diminish health-related or general quality of life (Kyle, Morgan, & Espie, 2010), and is closely tied to emotional and psychological health, particularly depressive symptoms (Fang, Tu, Sheng, & Shao, 2019; Hanson & Ruthig, 2012). Disturbed sleep has also been cited as a reason caregivers decide to move the care recipient to an institution (for instance, Afram et al., 2014). Caregivers report experiencing sleep disturbance for a variety of reasons, for instance, when the person they care for has physical or emotional care needs during the night (Arber & Venn, 2011; Gibson, Helm, Breheny, & Gander, 2021; Martin & Bartlett, 2007). Sleep can be disturbed by worries about the person being cared for, or future circumstances; and may persist once care provision has ended (Corey & McCurry, 2018; Gibson, Gander, & Jones, 2014; Hislop & Arber, 2006). More broadly, among bed-sharing partners, a spouse in poor health may disrupt sleep as a consequence of sleep-disturbing symptoms such as pain (Kotronoulas, Wengstroem, & Kearney, 2013; Walker, Luszcz, Hislop, & Moore, 2012) or as a consequence of distress caused by a relative suffering (Martire, Keefe, Schulz, Parris Stephens, & Mogle, 2013).

¹ Caregiver burden, according to the Zarit Burden Interview, can be defined as the perception of suffering in relation to emotional or physical health, finances and social life as a result of the provision of care (Zarit, Todd, & Zarit, 1986)

Caregivers of specific patient groups are often a subject of caregiver sleep research, particularly people with dementia (Byun, Lerdal, Gay, & Lee, 2016), as sleep disturbance is common among individuals with neurological disease (Pistacchi, Gioulis, Contin, Sanson, & Marsala, 2014; Zahed et al., 2021). Other more general caregiving situations may also provoke caregiver sleep disturbances related to the stress of caregiving (for instance, Sacco, Leineweber, & Platts, 2018). However, sleep disturbances among mid- and late-life caregivers could also be attributed to a wide range of other factors. For instance, normal changes in sleep occur with age and age-related health changes (Miner & Kryger, 2020), differences in socioeconomic status or health of caregivers and non-caregivers (Verbakel, Tamlagsronning, Winstone, Fjaer, & Eikemo, 2017), or changes in important social relationships (Walker et al., 2012). In relation to the COVID-19 pandemic, measures brought in to curtail the spread of the virus may have increased strain and brought new stressors to unpaid caregivers, with possible implications for their sleep, as elevated insomnia symptoms have been linked to pandemic-related difficulties (Morin et al., 2021; Wright, Steptoe, & Fancourt, 2021). Developing a better understanding of how caregiving, and among couples, partner health, are associated with sleep disturbance, builds evidence in an area of research relevant to policy makers aiming to support unpaid caregivers.

1.2 RESEARCH AIMS AND OBJECTIVES

This thesis investigates the relationship between unpaid caregiving and sleep disturbance among women and men in mid- and later life. It aims to examine the characteristics of caregiving, and periods of transition and stability that may be associated with sleep disturbance. Further, it aims to investigate the roles of co-resident care and partner health in the context of cohabiting couples. It considers whether these relationships differ by gender and in differing social circumstances, analysing English Longitudinal Study of Ageing (ELSA) data from 2008 to 2017 and carrying out cross-sectional analysis of data from June and July 2020 during the COVID-19 pandemic.

The caregiver stress process framework provided the foundation for the conceptual framework guiding the research, with additional insights incorporated from the sociology of sleep, and wider stress process approaches to health among couples. This led to a focus on the characteristics of care and the periods during caregiving that may be more likely to be stressful. Further focus was placed on differences by gender and incorporating partner health characteristics as an important aspect of the relationship context in which caregiving and sleep occurs. The thesis expands the characteristics of unpaid care that have been investigated in relation to sleep disturbance using population-based longitudinal data. Specifically, it examines the relationship with the care recipient (spouse, parent or other) and duration of care, contexts which may be related to sleep disturbance. It also examines partner health, co-resident care and sleep, in the context of cohabiting couples. Recent cross-sectional population-based caregiver sleep studies have addressed duration of care and care recipient condition. However, the results of these studies may be biased due to unobserved differences between caregivers and non-caregivers. The panel methods used in this thesis partially address omitted variable bias and provide evidence in an English context. Further, although caregiving transitions and caregiving hours have been investigated in recent longitudinal population-based caregiver sleep studies, these have not been considered among mid and late life adults in the English context, over the period when there were significant cuts to state-funded social care for older adults.

The thesis uses fixed effects models to assess changes within individuals, removing time-constant sources of confounding. This allows estimation closer to the unique effect of providing unpaid care on sleep disturbance. The statistical method has only recently been used in a handful of caregiver sleep studies. Analysis draws predominantly on three waves of the ELSA, spanning the period 2008/09 to 2016/17, waves 4, 6 and 8. These waves were selected as they included questions on sleep. Waves 3 to 8 were used to code care transitions and care duration variables² and the

² Waves 1 to 9 and the COVID-19 wave 1 data were used to re-code partner health variables, as advised was required by the ELSA team due to a problem with feed-forward information, see Methodology section 5.3 and Appendix B.

thesis took advantage of the availability of the first wave of ELSA COVID-19 data collected in June and July 2020, early in the pandemic.

1.3 THESIS STRUCTURE

The remainder of this thesis is structured as follows: *Chapter two: Background*, outlines the social context in which unpaid care occurs in the UK. This includes a brief consideration of trends in population ageing, life expectancy and health, the pressures on the social care system and the importance of unpaid care within this context. A brief overview of caregiver health is provided before defining sleep and sleep disturbance and discussing sleep as a contributor to health. The chapter ends by introducing caregiver sleep and the potential consequences of disturbed sleep for caregivers. *Chapter three: Literature review*, begins by outlining the characteristics of caregivers and possible selection factors involved in decisions to provide unpaid care, as well as the determinants of sleep disturbance. It then provides a critical assessment of what is known about caregiver sleep in relation to the characteristics of the caregiver, caregiving situation and care recipient that are associated with caregiver sleep disturbance. *Chapter four: Theoretical perspectives on caregiver sleep*, outlines the theoretical perspectives that have informed the research, predominantly the caregiver stress process framework, with additional insights from stress process approaches to health among couples and the sociology of sleep. The combined approach contributes an understanding of the importance of gendered social roles to the relationships between caregiving and sleep disturbance, and the potential role of partner health, particularly in the context of sleep among couples. *Chapter five: Methodology*, describes the study data, the variables and their measurement, and the descriptive and inferential statistics used. It includes information on approaches taken to weighting, missing data and sensitivity analyses. The main methodological approach chosen for the study, fixed effects models, is described and compared to other possible approaches, such as random effects and within-between random effects models. *Chapter six: Descriptive statistics*, presents the cross-sectional samples from waves 4, 6 and 8, the three main waves of data used in subsequent longitudinal analyses. Next, demographic, socioeconomic and health characteristics are described by gender and caregiving characteristics: hours of care, relationship with the care recipient and location of care.

An explanation is also provided of the process for selection of the longitudinal samples used in chapters seven to nine. Chapters seven to nine describe the results of analyses for each research question.

Chapter seven: Caregiving hours, relationship with the care recipient and sleep disturbance, first sets out and interprets the results of longitudinal fixed effects model analyses of caregiving hours and sleep disturbance over three waves of data. This is followed by analysis of the caregiver relationship to the care recipient and sleep.

Chapter eight: Caregiving transitions, care duration and sleep disturbance, first presents investigations of associations between caregiving transitions and sleep disturbance, followed by care duration and sleep disturbance. Caregiving transitions are analysed using fixed and random effects models (sleep disturbance) and using pooled multinomial logistic regression (change in sleep disturbance). Analysis of care duration is conducted using random effects models. *Chapter nine: Coresident caregiving, partner health and sleep among couples*, analyses how co-resident care and partner health are associated with sleep disturbance, among cohabiting couples. Multilevel models and fixed effects models analyse the cross-sectional and longitudinal samples from the ELSA main waves, while logistic regression is used to analyse data collected during the COVID-19 pandemic. *Chapter ten: Conclusions*, discusses the findings from chapters six, seven, eight and nine in relation to previous studies and the theoretical perspectives underpinning the thesis. Contributions to theoretical development and strengths and limitations of the research are also assessed. Finally, brief comments are made on future research possibilities and implications for policy and practice. *Appendices A to F* provide additional information and sensitivity analyses not presented in the main text after the list of references used in the thesis.

Chapter two - Background

2.1 INTRODUCTION

This chapter sets the context for carrying out research into caregiving and sleep disturbance, the subject of the thesis. Section 2.2 defines unpaid care, provides a brief description of the demographic and social factors contributing to a growth in demand for unpaid care and the importance of unpaid care in the context of English social care. It then sets out the challenges to the English social care system that have exacerbated the need for unpaid care. The section predominantly focuses on changes to social care between 2008 and 2017, consistent with the period of available data used in the study. However, brief comments are made on developments relevant to the coronavirus pandemic, the subject of analysis in the second half of chapter nine. A brief overview of evidence linking care provision to wider health and wellbeing is provided in section 2.3. Section 2.4 defines sleep and sleep disturbance and outlines evidence on sleep disturbance as a contributor to health and wellbeing. The reasons caregivers may experience sleep disturbance are described in section 2.5, along with evidence of the potential consequences of sleep disturbance for caregivers. Finally, a summary concludes the chapter in section 2.6.

2.2 THE CONTEXT OF UNPAID CARE IN ENGLAND

Demographic, health, and social changes are contributing to a growing demand for social care, particularly unpaid care, in the UK, as in other European countries (Agree & Glaser, 2009). The number of individuals receiving state-funded social care has decreased over the past two decades in England (Glasby et al., 2021) and alternative sources of paid care are of limited availability (Bottery, 2021b). Consequently, the availability of unpaid care, and the health and wellbeing of caregivers is of increasing importance to policy makers (Brimblecombe et al., 2018). These population trends and social care pressures are the subject of this section.

2.2.1 Definition of unpaid care

There is no single accepted definition of unpaid care but most definitions include the provision of additional help, outside of employment, to someone needing support for reasons of mental or physical ill health, or needs associated with older age (Arber & Ginn, 1995; Rutherford & Bu, 2018). This enables care provided without payment by family or friends to be distinguished from paid care work as part of the formal care economy (Fine, 2004)³. Interpretation of activities as unpaid care, rather than normal familial responsibilities, may differ among individuals, for instance by gender (Arber & Ginn, 1990). Informal care and family care, also used in the literature, cover similar activities (Del Bono, Sala, & Hancock, 2009). The terms caregiver and care recipient are used in the thesis to denote individuals undertaking unpaid care and receiving unpaid care. Each term has been contested. For instance, caregiver may lack relevance to certain groups (Larkin & Milne, 2014; Molyneaux, Butchard, Simpson, & Murray, 2011) and over simplify “a complex cluster of social activities, behaviours and dispositions” (Fine, 2004, p228). Care recipient may imply passive receipt, though there is often a reciprocal exchange of care or other forms of help among couples or parent and child, either concurrently or at another time (Larkin & Milne, 2014; Raschick & Ingersoll-Dayton, 2004). Nonetheless, these terms are prevalent in the literature and are used in this thesis, acknowledging these difficulties with their use.

2.2.2 Unpaid care and the social care system

A Local Authority (LA)’s duty to provide care and support, social care, is defined in the Care Act 2014 as promoting individual wellbeing (Care Act, 2014). Wellbeing in this context includes individual mental and physical health, personal dignity and ability to participate in social and work life (Care Act, 2014). In practice, social care encompasses support for individuals with daily activities such as washing, eating or paying bills, as well as social and emotional support (Humphries et al., 2016). Such care is predominantly provided by unpaid caregivers (National Audit Office, 2018), comprising nearly one in four women and 17% of men in 2017/18 (Zhang, Bennett, & Yeandle, 2019). If valued equivalently to a paid public service, unpaid care contributed between

³ A small proportion of caregivers receive a direct payment from their Local Authority in England to support their wellbeing or Carers Allowance if they care for more than 35 hours per week (National Audit Office, 2018).

£56 billion and £100 billion of support to individuals with care needs in 2016/17 (National Audit Office, 2018). This far exceeded LA social care services, NHS-funded contributions and estimates of self-funded care, amounting to £32 billion in total (National Audit Office, 2018). As the next section highlights, unpaid care is expected to be of increasing importance in the future.

2.2.3 Future need for, and supply of, unpaid care

While the percentage of working age adults with a disability has risen slightly in recent years (Department for Work and Pensions, 2021) and more young people are living with disabilities in the community (Glasby et al., 2021), future increased demand for unpaid care is predominantly driven by care needs among older people (Brimblecombe et al., 2018). In the UK, the percentage of people aged 65 and over has risen over the past two decades to 18% in 2019 and is expected to reach 25% by 2050 (United Nations, 2020). This population ageing was initially due to decreases in fertility, but is now largely driven by reductions in mortality (Murphy, 2017), a testament to improvements in public health, medical advances, and social and economic growth (United Nations, 2020). While life expectancy growth slowed from 2011 (Marmot, Allen, Boyce, Goldblatt, & Morrison, 2020; Murphy, 2021), overall, projections foresee a doubling of individuals aged 85 and over from 2018 to 2043 (Nash, 2020). However, whether these additional years of life are likely to be lived with or without disability and ill health is the subject of ongoing research. Some studies have found later cohorts are more likely to have poor self-rated health, diabetes and cardiovascular disease (Jivraj, Goodman, Pongiglione, & Ploubidis, 2020; Welsh, Matthews, & Jagger, 2021), while others find slight increases in years lived in good health (Murphy, 2021). Despite the uncertainty in future health trends, these changes are consequential for unpaid care. Increases in the absolute numbers of older individuals, and increasing complexity of care due, for instance, to multimorbidity, indicate a substantial rise in likely future needs for care (Brimblecombe et al., 2018; Kingston, Comas-Herrera, Jagger, & MODEM Project, 2018).

The availability of unpaid caregivers is influenced by social trends such as declining family size, family dispersal over larger geographical distances and increasing

employment among women (Agree & Glaser, 2009). The number of older spouse caregivers, who themselves may have care needs, is expected to increase with rising life expectancy and more rapid increases in cohabiting couples surviving together than individuals living alone (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). However, adult caregivers providing at least 20 hours of care per week to parents are projected to increase only modestly from 2007 to 2032, leaving a large care gap (Pickard, 2015). Brimblecombe and colleagues forecast a gap of 0.9 million caregivers in 2025 and 2.3 million caregivers by 2035 (Brimblecombe et al., 2018). This estimate assumes constant disability rates and requirements for care, a static ratio of caregivers to care recipients, and an increase in the availability of formal care services, requiring a reversal of the trend in services over recent decades (Brimblecombe et al., 2018).

2.2.4 Social care pressures

Concurrent with the rise in individuals requiring care, pressure has built over the last two decades within the social care sector. Pressures include increasing service costs, a workforce crisis, and Central Government funding changes (Glasby et al., 2021; Humphries et al., 2016). For instance, between 2009/10 and 2014/15, large cuts (median 36%) were made in central Government grants to LAs because of the 2008 recession (Innes & Tetlow, 2015). Most LAs initially protected adult social care (Glasby et al., 2021). However, despite rising demand, spending cuts have been most acute across services for individuals aged 65 and over, not in services for working age adults (Glasby et al., 2021). Social care spending for older adults dropped by 19% from 2009/10 to 2017/18; a 31% drop in per capita spending, due to population ageing (Crawford et al., 2021). The number of individuals supported fell by 280,000, or 26%, between 2009/10 and 2013/14, predominantly among those receiving home care (Crawford et al., 2021). By the time the pandemic occurred (investigated in chapter nine), social care funding was beginning to increase, due to additional Council Tax raising opportunities through the social care precept⁴ and ad hoc funding provided by central Government (Burchardt et al., 2020; National Audit Office, 2018). However, these funding increases are considered inadequate to mitigate the pressures on services

⁴ Central Government allowed LAs to charge an additional 2% (2016/17), up to 3% (2017/18) and up to 6% (2018/19) on Council Tax, ring-fenced for social care; most beneficial for LAs serving the least deprived areas (Burchardt, Obolenskaya, & Hughes, 2020).

(Glasby et al., 2021). This necessitates more individuals with care needs to rely on unpaid caregivers, arrange self-funded care or be left with unmet needs (Iparraguirre, 2020b).

The likely impact on unpaid caregivers may be particularly pernicious among women, whose care has been found to partially substitute LA-funded services (Iparraguirre, 2020a). Lower LA social care spending has been associated with increases in caregiving of 20 or more hours per week (Zigante, Fernandez, & Mazzotta, 2021) and poorer caregiver wellbeing, particularly when caregiving for 35 or more hours (Zhang, Bennett, & Yeandle, 2021). More limited availability of services may therefore mean new caregivers have to provide more intense care, or existing caregivers provide more care hours, at the possible detriment to their health and wellbeing (Zhang et al., 2021; Zigante et al., 2021). Recent announcements include £5.4 million over 3 years to implement a cap on care costs and improve social care, and the Social Care White Paper, published in December 2021 (Department of Health and Social Care, 2021). These have offered some, but little, hope of significant and well-funded reform, which may be of benefit to caregivers (Bottery, 2021a). With increasing demand and reductions in LA spending, understanding the implications of caregiving for caregivers is an important contribution to knowledge and useful for developing support services in line with caregiver needs.

2.2.5 Support for unpaid caregivers

The enactment of the Care Act 2014 (Care Act, 2014) brought into legislation important new responsibilities for local authorities to promote individual wellbeing, including among caregivers (Fernandez et al., 2020). The right to a carer assessment, irrespective of care recipient need or intensity of care provided, and an LA requirement to provide information and advice, were key changes relating to caregivers (Fernandez et al., 2020). Contrary to expectations, in the two years following the Care Act, 2014, carer assessments and receipt of services decreased (Fernandez et al., 2020). Pressures in the social care system outlined above constrained the transformation aspired to in legislation (Burchardt et al., 2020; Fernandez et al., 2020; Pickard, King, & Knapp, 2016). While change is currently limited, the Care Act, 2014's emphasis on wellbeing

provides the legislative intent to provide better support for caregivers. However, although social care funding has begun to increase as noted above, from 2020, the COVID-19 pandemic brought unprecedented pressures on the social care system and on unpaid caregivers, providing the background for final analyses in chapter nine.

2.2.6 COVID-19 pandemic and unpaid caregivers

On 11th March 2020, the World Health Organisation declared the spread of the coronavirus disease, COVID-19, caused by the SARS-CoV-2 virus, a pandemic (WHO, 2020). The data used in chapter nine to analyse co-resident caregiving and sleep quality during the pandemic was collected between 3rd June 2020 and 26th July 2020 (NatCen Social Research, 2020c). At that point, the rhythms of daily life had been disrupted by the introduction of social distancing, hygiene behaviours and a series of national and regional lockdowns (UK Health Security Agency, 2020-2021). The pandemic and resultant changes affected some individuals more than others, for instance, via greater exposure to the virus, differential access to buffering resources, such as social support and personal savings, or underlying health vulnerability to its effects (Rose, Manning, & Bentall, 2020; Settersten et al., 2020; The Lancet, 2020). Deep-rooted challenges of the social care system were exacerbated, most prominently, those in nursing and residential homes, but also within the home care sector, among individuals with care needs and their caregivers (Foster, 2021; Onwumere et al., 2021; Suleman et al., 2021). As more data has become available, analysis has begun to uncover complex patterns of resilience and failure of supply in unpaid and formal care across countries in Europe (Tur-Sinai, Bentur, Fabbietti, & Lamura, 2021). In the UK, a large increase in unpaid caregiving and voluntary sector support secured basic food and support for many (Chatzi, Di Gessa, & Nazroo, 2020; Evandrou, Falkingham, Qin, & Vlachantoni, 2020). However, unpaid caregivers reported numerous difficulties during the pandemic, including difficulty accessing health services, closure of community and respite services and loneliness and isolation (Alzheimer's Society, 2020; Bennett, Zhang, & Yeandle, 2020b; Carers UK, 2020; Giebel, Pulford et al., 2021; Leggett et al., 2021; Sriram, Jenkinson, & Peters, 2021). Many community-based opportunities for socialising and respite closed early on in the pandemic (Giebel, Cannon et al., 2021; Giebel et al., 2021) and caregivers expressed worries about declining physical health and reduced contact

for the person they cared for (Lightfoot et al., 2021). Rapid disease progression was noted among some people with neurological conditions, including worsening sleep (Cagnin et al., 2020; Kumar et al., 2021; Li, Zhang, Zhang, Li, Ma, An, Chen, Liu, Kuang, Yu, & Wang, 2021b; Penteadó et al., 2020). In the UK, although many paid home care services remained operational (Carers UK, 2021b), caregivers had to make unenviable choices. Some caregivers limited contact with others outside their own household despite their need for support and to the detriment of the person they cared for (Samsi, Cole, Orellana, & Manthorpe, 2022). Other caregivers (and care recipients) chose to continue to receive paid home care workers despite infection risks, worrying they might otherwise lose hard-won support (Giebel et al., 2021). These all suggest the pandemic brought new stressors, and increased existing caregiving and non-caregiving stressors, at least for some individuals (Samsi et al., 2022).

2.3 CAREGIVING AND WIDER HEALTH AND WELLBEING

Relationships between caregiving and health, particularly poorer health and wellbeing, is a dominant research theme (Larkin, Henwood, & Milne, 2018). Much of the literature on caregiver health has found caregiving to be detrimental for psychological and sometimes physical health, including being associated with a greater risk of mortality (Capistrant, 2016; Pinqart & Soerensen, 2011; Schulz & Beach, 1999). However, small cross-sectional studies of relatively homogenous groups of caregivers have dominated the literature (Pinqart & Sörensén, 2003). Such studies have been critiqued for using non-random samples, selecting caregiving groups most likely to be under strain and either not comparing to non-caregiving groups, or making poorly matched comparisons (Brown, R. M. & Brown, 2014; Roth, Fredman, & Haley, 2015). Similar comments have been made about the much smaller caregiver sleep literature (Byun et al., 2016; Peng & Chang, 2013). Longitudinal analyses of population-based data have served to address these critiques in the caregiver health literature. For instance, studies provide evidence that is generalisable to the wide range of caregiving situations among the general population, something which is not possible when evidence is drawn from sub-groups such as caregivers of people with dementia. Evidence of benefits of care provision are increasingly documented, for instance in satisfaction and self-esteem (Freedman, Cornman, & Carr, 2014; Pristavec, 2019; Raschick & Ingersoll-Dayton, 2004) and, in

some studies, cognitive function⁵ (Yuan & Grün, 2020). Further, analysis of the heterogeneity of caregiving circumstances and the characteristics of the caregiver have provided a more nuanced picture of relationships between caregiving and health (Bom, Bakx, Schut, & van Doorslaer, 2018). For instance, intensive care and co-resident care have often been linked to greater depressive symptoms and distress (Caputo, Pavalko, & Hardy, 2016; Hiel et al., 2015; Hirst, 2005; Kaschowitz & Brandt, 2017), particularly among women (Bom, Bakx, Schut, & van Doorslaer, 2019). In contrast, lower intensity care and non-resident care may be neutral for health or have some health benefits (Bom & Stöckel, 2021; Kaschowitz & Brandt, 2017). Studies increasingly aim to understand how care and health may vary over time (Yuan & Grün, 2020) and at particular transition points over a caregiving episode (Rafnsson et al., 2017; Sacco et al., 2022; Uccheddu, Gauthier, Steverink, & Emery, 2019). In relation to mortality, some studies have found evidence of reduced risk of mortality among caregivers (Brown et al., 2009; Maguire, Rosato, & O'Reilly, 2017; Ramsay, Grundy, & O'Reilly, 2013). However, results can differ markedly dependent on the measure of caregiving used (Mehri, Kinney, Brown, & Rajabi Rostami, 2019). The importance of investigating this heterogeneity among unpaid caregivers and potential differences in association with sleep disturbance is a key element of this thesis. A further aspect of heterogeneity related to unpaid care is the possibility of selection bias, where existing differences in health and other characteristics such as socioeconomic status, or attitudes and motivation to care, make it more or less likely that an individual will become an unpaid caregiver (Kaschowitz & Brandt, 2017; van Groenou & De Boer, 2016). Influential factors in the provision of unpaid care, as well as risk factors for sleep disturbance that are commonly available in nationally representative surveys, are discussed in the literature review, section 3.3 and 3.4. In addition to controlling for concurrent confounding factors, addressing selection into caregiving is important for approaching a causal understanding of caregiving's effect on health, and in this thesis, sleep, and has methodological implications (de Zwart, Bakx, & van Doorslaer, 2017). This research uses fixed effects models which remove time-constant sources of variation between individuals. In doing so the models remove time-constant observed and unobserved differences between individuals, partially addressing selection into caregiving, see

⁵ This study used a general definition of caregiving and results among other studies are equivocal.

Methodology section 5.4. Another important possible confounder is the presence of a family member in ill health, a factor in the decision to provide care (Brown & Brown, 2014). Studies including family health data attempt to distinguish between health effects related to care provision and those associated with simply having an ill family member, which can be stressful, irrespective of care provision (Amirkhanyan & Wolf, 2003; Bobinac, van Exel, Rutten, & Brouwer, 2010; Brown & Brown, 2014). Partner health is incorporated into analysis of caregiver sleep in chapter nine of this thesis. Sleep is an important contributor to health and wellbeing, part of the impetus to investigate its relationship with caregiving. These sleep-health linkages are discussed in the next section.

2.4 SLEEP DISTURBANCE, HEALTH, AND WELLBEING

This section defines sleep and sleep disturbance, then addresses evidence of links between sleep, health, and wellbeing, before considering qualitative accounts of sleep disturbance from caregivers and evidence of the impact poor sleep may have on caregiver health and wellbeing.

2.4.1 Sleep and sleep disturbance

From a biological point of view, sleep is an essential, reversible, physiological, and behavioural state (Crowley, 2011; Phillips, 2018). It is naturally occurring, has a circadian cycle and entails a loss of sensory awareness such that an individual is not aware of being asleep or experiencing the external world (Dement & Vaughan, 2000). Yet sleep practices are also influenced by social and cultural contexts (Williams, 2002). They are malleable to a certain extent (Venn & Arber, 2012), for instance to accommodate shift work (Kecklund & Axelsson, 2016) and, as discussed in section 2.5, night-time care (for instance, Arber & Venn, 2011). Sleep's function is as yet not fully understood, but it is thought to be important in restorative processes including maintenance of cardiovascular and metabolic processes, improving brain function and waking performance (Krueger, Frank, Wisor, & Roy, 2016; Phillips, 2018). These functions indicate possible mechanisms by which poorer sleep may be related to poorer health and wellbeing, discussed in section 2.4.2 (Cappuccio & Miller, 2018).

Biologically, sleep is characterised by neurological changes in the brain and physiological responses over the course of a night, termed sleep architecture (Crowley, 2011). Sleep comprises aspects of timing, duration, quality, and variability (Matricciani et al., 2018). Further, it can be measured objectively, or via subjective perceptions of an individual about their own sleep (Matricciani et al., 2018). Objective neurological data can characterise patterns of sleep, disturbance, and wakefulness, measured using polysomnography and other techniques requiring specialist equipment (Buysse et al., 2010). Data is often captured over one or a few days in a clinical or, more rarely, a home setting (Fonareva, Amen, Zajdel, Ellingson, & Oken, 2011; Peng & Chang, 2013). Body movements can also be collected, often using wrist-based devices, allowing longer periods of data collection (Peng & Chang, 2013). Strong correlations between sleep or wakefulness and body movements enable sleep-wake patterns to be inferred from this data (Buysse et al., 2010). Body-worn device data is increasingly being collected in nationally representative studies (Matricciani et al., 2018), as will be the case for ELSA wave 10 (English Longitudinal Study of Ageing, 2021). Subjective data can be collected via sleep diaries or survey questions relating to varying periods of time from days to months (Buysse et al., 2010). Subjective measurement items and scales are numerous, one review of the literature finding over 100 sleep questionnaires (Buysse et al., 2010). Measures used in epidemiological studies include sleep duration, sleep quality, general sleep disturbances, and specific sleep disorders (Knutson et al., 2017).

Most epidemiological research has been carried out on sleep duration, measured continuously or using varying definitions to create categories of short, optimal and long sleep. The US-based National Sleep Foundation has published recommended sleep durations by age, from expert consensus of available data (Hirshkowitz, Whiton, Albert, Alessi, Bruni, DonCarlos, Hazen, Herman, Adams Hillard et al., 2015). Based on studies of sleep duration and general, emotional, cognitive, and physical health, sleep durations of 7-9 hours (adults aged 25-64) and 7-8 hours (older adults aged 65 or over) were recommended (Hirshkowitz et al., 2015). Although sleep duration is frequently the subject of epidemiological studies, caregiver accounts of their sleep focus on sources of disruption rather than total length of time asleep. Further, duration is difficult to assess

as sleep is liminal, individuals are unaware of falling asleep (Meadows, Nettleton, Hine, & Ellis, 2021) and working age and older adults have differing opportunities to add to sleep time through daytime napping (Hirshkowitz et al., 2015). Consequently, duration can be difficult for individuals to estimate. This may be a particular difficulty for individuals reporting having light or alert sleep as has been reported by some caregivers (Arber & Venn, 2011). This thesis focused on sleep disturbance for these reasons.

There is no one definition of sleep disturbance or sleep quality and these terms are sometimes used interchangeably in caregiver sleep studies (Peng & Chang, 2013). Sleep quality can be thought of as a latent construct, individuals assessing their sleep across many dimensions (Buysse et al., 2010). Objective measurements, such as sleep latency, the time taken to fall asleep; or sleep efficiency, the ratio of total sleep time to time in bed, can imply good or poor sleep quality (Ohayon et al., 2017). Sleep disturbance can be defined as disruptions to sleep resulting in wakefulness (Buysse et al., 2010). Disturbances may be caused by a wide variety of behavioural, physiological, psychological, and environmental factors, which can vary across, and be influenced by, social dynamics (Arber, Hislop, & Williams, 2007; Buysse et al., 2010). Sub-clinical sleep disturbances are common, one study estimating 38% of British adults had two or more difficulties with sleep on at least a minority of nights (Groeger, Zijlstra, & Dijk, 2004). Objective assessment of sleep disturbance includes through sleep latency or wake after sleep onset, the amount of time spent awake after initially falling asleep and before final awakening (Ohayon et al., 2017). As noted above, a wide range of subjective measurements are available. Two validated scales, often the basis for the development of sleep modules in population-based surveys, are the Pittsburgh Sleep Quality Index, PSQI (Buysse, Reynolds III, Monk, Berman, & Kupfer, 1989), and the Jenkins Sleep Problems scale (Jenkins, Stanton, Niemcryk, & Rose, 1988). PSQI assesses sleep using nineteen questions across seven sub-scales, encompassing sleep disturbances, duration, and quality, offering an overall scale, where a score greater than 5 indicates sleep disturbance (Buysse et al., 1989). Jenkins Sleep Scale, JSS, focuses on three or four questions (depending on the version of the scale) addressing commonly occurring sleep problems (Jenkins et al., 1988). This thesis measures sleep disturbance using questions

based on the Jenkins Sleep Scale, on difficulty with going to sleep, staying asleep and waking up tired, assessed subjectively over a period of one month, see Methodology section 5.3. The questions are common symptoms of insomnia. Sleep disorders such as insomnia; sleep-disordered breathing, including obstructive sleep apnoea; and sleep movement disorders such as restless legs syndrome, are increasingly common in later life (Crowley, 2011). Their measurement is rarely incorporated into nationally representative surveys due to the complexity and volume of information required to characterise each condition. For instance, diagnosis of insomnia disorder and sub-types can involve sleep history, duration, frequency, severity, possible causes, and daytime consequences (Buysse, Ancoli-Israel, Edinger, Lichstein, & Morin, 2006). Concluding this introduction to sleep disturbance, it is important to note that while sleep is often assessed in studies through one of the dimensions described above, some researchers question such simple measurement of a complex phenomenon (Meadows et al., 2021). New ways of characterising sleep across multiple dimensions have been proposed, for instance, developing a broader conceptualization of sleep health (Buysse, 2014; DeSantis et al., 2019; Knutson et al., 2017). Although measurement of sleep is complex and varies widely by study, increasing evidence indicates disturbed sleep is related to poorer health and wellbeing.

2.4.2 Sleep disturbance, health, and wellbeing

Evidence is amassing of complex, sometimes bidirectional, associations between sleep and psychological and physical health, as well as aspects of day-to-day wellbeing and quality of life (Fung et al., 2016). Most studies have focused on sleep duration, often finding short sleep to be associated with poorer health outcomes and sleep duration of 6-8 hours related to lowest risk of poor health (Cappuccio & Miller, 2018). Associations between short sleep duration and increased risk of cardiometabolic conditions have been argued to reflect causality due to their strength, temporality, and existence of plausible mechanisms (Cappuccio & Miller, 2018). Associations have also been found with long sleep duration, though convincing causal mechanisms have yet to be identified and sleep may be a marker of underlying, sub-clinical, poor health (Ferrie, Kumari, Salo, Singh-Manoux, & Kivimäki, 2011; Hirshkowitz et al., 2015). Evidence of these links has provoked adoption of (Hirshkowitz, Whiton, Albert, Alessi, Bruni,

DonCarlos, Hazen, Herman, Katz et al., 2015), or planning for, guidelines on recommended sleep duration (Department of Health and Social Care, 2019). This thesis focuses on sleep disturbance, for which there is a similar, if smaller, body of evidence. Severe sleep disturbance has been associated with living disease-free for three fewer years and in good health for six fewer years than those with no sleep disturbance (Stenholm et al., 2018). In relation to cardiometabolic health, links have been found between sleep disturbance and obesity (Fatima, Doi, & Mamun, 2016), diabetes (Anothaisintawee, Reutrakul, Van Cauter, & Thakkestian, 2016; Cappuccio, D'Elia, Strazzullo, & Miller, 2010), hypertension and cardiovascular diseases (Sofi et al., 2014). Inter-related physiological mechanisms are suggested through neurological, hormonal and energy metabolism pathways (Cappuccio & Miller, 2018).

Regarding psychological health, sufficient quality and quantity of sleep is associated with more positive, and fewer negative, emotions (Hanson & Ruthig, 2012). Disturbed sleep has been associated with anxiety (Kay & Dzierzewski, 2015), lower health-related quality of life (Kyle et al., 2010; Lee et al., 2009) and, via a large body of literature, depression (Kay & Dzierzewski, 2015). Sleep disturbance is a common early symptom of depression among older adults (Jackowska, Kumari, & Steptoe, 2013; Skapinakis et al., 2013). However, sleep disturbance and depression may be independent risk factors for each other (Baglioni et al., 2011; Bao et al., 2017; Fang et al., 2019; Poole & Jackowska, 2018), with common genetic, environmental and social risk factors (Staner, 2010). Sleep disturbance and depression co-occur in 11% of adults aged 60 and over (Bao et al., 2017).

Links have also been found between sleep disturbance, work performance, and cognition. For instance, greater trouble sleeping has been associated with more absences from work and lower self-rating of work performance (Hui & Grandner, 2015), while sub-clinical sleep disturbance has been found to increase the risk of workplace accidents (Uehli et al., 2014). In healthcare studies, nurse ratings of the quality of care they provide have been found to reduce when nurses reported shorter sleep the day before (Stimpfel, Fatehi, & Kovner, 2020). Such results indicate possible consequences of sleep disturbance that could occur among unpaid caregivers, with potentially

damaging consequences for caregiver mental health and for care recipient wellbeing, discussed in section 2.5.2. In relation to cognitive impairment, early evidence suggests links between neurological conditions and sleep disturbances may be bidirectional. Sleep disturbance can be a symptom of conditions such as dementia (Vaz Fragoso & Gill, 2007) and can worsen disease progression in Parkinson's disease (Zahed et al., 2021). It may also be a risk factor for cognitive impairment (Devore, Grodstein, & Schernhammer, 2016; Robbins et al., 2020) and the development of dementia (Macedo, Balouch, & Tabet, 2017). Whether these are causal associations, or due to confounding by other risk factors such as cardiovascular disease is the subject of continued research (Livingston et al., 2020). These links are a reason for researching caregiver sleep, as supporting caregivers to maintain their health and wellbeing is important in supporting them to continue to provide care.

2.5 CAREGIVING AND SLEEP DISTURBANCE

2.5.1 Caregiver descriptions of sleep disturbance

Qualitative studies provide caregiver accounts of sleep disturbance, describing patterns of broken sleeping initiated or sustained by their own or their partner's activities. Sleep can be disrupted when attending to care recipients wandering or falling out of bed, needing night-time care or emotional support (Arber & Venn, 2011; Bianchera & Arber, 2007; Gibson et al., 2021; Martin & Bartlett, 2007). For instance, people with dementia may display automatic behaviours during the night such as getting up and dressed without remembering during the day (Gibson et al., 2014). Caregivers may develop altered sleep routines, going to bed later or sleeping lightly to better monitor the person they care for, to carry out domestic tasks or for personal relaxation, to the detriment of their own sleep (Arber & Venn, 2011; Bianchera & Arber, 2007; Gibson et al., 2021; Martin & Bartlett, 2007). Worries about the care recipient, longer term concerns about the future and sadness at a changing relationship can also disturb sleep (Arber & Venn, 2011; Bianchera & Arber, 2007; Gibson et al., 2014; Hislop & Arber, 2003a; Simpson & Carter, 2013a). Although many accounts of caregiver sleep disturbance stem from co-resident caregivers, those not living with the care recipient may be disturbed by confused night-time phone calls or requests for help (Arber & Venn, 2011; Simpson & Carter, 2013a). Following the end of care provision, disturbed sleep patterns can

remain. Former caregivers indicate feelings of guilt at moving the person they cared for into residential care (Arber & Venn, 2011). Waking with distressing memories of the last stages of caregiving is another reason for sleep disturbance, leaving a “legacy of caregiving” on sleep (Arber & Venn, 2011; Bianchera & Arber, 2007; Corey & McCurry, 2018). Some caregivers report sleep patterns improve slowly on ceasing care, but do not return to pre-caregiving quality (Corey & McCurry, 2018). These patterns suggest disturbed sleep may be an outcome of stressors relating to the direct provision of care at night or the need to reduce sleep in order to balance other aspects of life (Arber & Venn, 2011; Gibson et al., 2014; Gibson et al., 2021; Hislop & Arber, 2006). Sleep may also be disturbed due to disruptions caused by sharing a bed with someone who themselves has disturbed sleep caused by illness-related symptoms (Arber & Venn, 2011; Gibson et al., 2014; Gibson et al., 2021; Hislop & Arber, 2006; Peng & Chang, 2013). The next chapter reviews the quantitative evidence of associations between caregiving and sleep disturbance, as well as potential factors important to account for in analyses in the thesis. A range of review articles have previously synthesised sections of the caregiver sleep literature, predominantly focusing on studies of caregivers of people with dementia (Gao, Chapagain, & Scullin, 2019; Kim, H. & Rose, 2011; Lee & Thomas, 2011; McCurry, Logsdon, Teri, & Vitiello, 2007; Peng & Chang, 2013; Peng, Lorenz, & Chang, 2016; Waligora, Bahouth, & Han, 2018) and different forms of cancer (Kotronoulas, Wengstrom, & Kearney, 2013; Maltby, Sanderson, Lobb, & Phillips, 2017; Pawl, Lee, Clark, & Sherwood, 2013b). Several include more general caregiving situations (Byun et al., 2016; Kotronoulas et al., 2013; Leggett, Morley, & Smagula, 2020; McCurry, Song, & Martin, 2015), however none have reviewed the most recent population-based caregiver sleep studies, which are the primary focus of the next chapter. Previous review authors noted limitations of the literature including the dominance of cross-sectional studies based on small samples of caregivers, often without caregiving controls (Byun et al., 2016). Limited use of theory, and inconsistent adjustment of multivariable analyses were also highlighted (Peng & Chang, 2013). Authors asserted the need for more studies to investigate changes in caregiving and sleep over time (Byun et al., 2016; Peng & Chang, 2013) and sleep among caregiving dyads, including care recipient factors (Kotronoulas et al., 2013). Some studies have focused on the consequences of disturbed sleep specifically among caregivers, discussed in the next section.

2.5.2 Possible consequences of disturbed sleep for caregivers.

While some caregivers report acceptance of disturbed sleep, taking steps to mitigate its effects (Gibson et al., 2014), caregiver accounts also note fatigue and the possibility that improved sleep would allow them to cope better with their situation (Gibson et al., 2021). Indeed, caregiver mood, measured by negative affect (McCrae et al., 2016) and morning anger (Marini, Martire, Jones, Zhaoyang, & Buxton, 2020), has been found to be worse after nights of perceived poor sleep quality. Care recipient night-time wandering and sleep disturbances can be important contributors to caregiver decisions to institutionalise a care recipient (Afram et al., 2014; Gibson & Gander, 2021; Pollak & Perlick, 1991). Disturbed sleep may also affect caregiver employment. For instance, caregiving-related sleep disturbance was positively associated with days of absence from work in the United States (Robbins et al., 2022). In relation to caregiver health, care recipient sleep disturbance has been linked to greater caregiver burden, poorer health-related quality of life and life satisfaction (Bartolomei et al., 2018; Okuda et al., 2019; Perez, Perrin, Lageman, Villaseñor, & Dzierzewski, 2020) and poorer mental and physical health (Al-Rawashdeh, Lennie, & Chung, 2017; Lam, 2008). Poor caregiver sleep has been associated with reduced health-related quality of life in the caregiver (Al-Rawashdeh et al., 2017; Chang, Tsai, Chang, & Tsao, 2007; Creese, Bedard, Brazil, & Chambers, 2008; Cupidi et al., 2012; Lam, 2008; Pawl et al., 2013b) and poorer physical function (Spira et al., 2010). For instance, among caregivers of people with psychosis, sleep quality partially mediated the relationship between negative thoughts about caregiving and poorer mental health (Smith, Onwumere, Craig, & Kuipers, 2019). Evidence is drawn predominantly from small studies and sleep has been found to relate to depressive symptoms and caregiver burden in complex ways (Fredman, Gordon, Heeren, & Stuver, 2014; Wang, Yip, & Chang, 2016). Although fewer studies have considered physical health in relation to caregiver sleep, sleep disturbance has been linked with metabolic markers of cardiovascular disease in some (von Kaenel et al., 2006), though not all studies (Schwartz, J. et al., 2013). For instance, higher caregiver wake after sleep onset has been associated with elevated blood coagulants (Mausbach et al., 2006).

2.6 CONCLUSION

Unpaid caregivers provide the primary form of support for most individuals needing help to live independently, safely and well. Future growth is predicted in the need for unpaid care, due to the increasing number of older adults requiring support and the limited support available through the social care system. In fact, unpaid care occurs in the context of under investment in the social care system, limited practical support for caregivers, and since 2020, the consequences of the coronavirus pandemic. Caregiver wellbeing is now formally acknowledged as being of central importance to maintaining individuals in their caregiving roles. A large literature has investigated how caregiving is associated with measures of health, providing evidence for policy and practice supporting caregivers in their roles. Sleep disturbance is important in this context due to the increasing evidence of associations with health problems and decreased wellbeing. Caregivers report detrimental effects on their sleep due to provision of night-time care, characteristics of the care recipient and wider worries. Consequences of sleep disturbance among caregivers, in addition to those for the general population, may include reduced care quality and be a provoking reason for institutionalisation of the person receiving care. The next chapter synthesises the existing literature on caregiver sleep, identifying gaps in knowledge where this thesis makes its contribution.

Chapter three - Literature review

3.1 INTRODUCTION

This chapter reviews the available evidence on the relationship between unpaid caregiving and sleep disturbance, identifying the research gaps to be addressed in the thesis. The review has two aims, first, to identify demographic, socioeconomic and health factors associated with the provision of unpaid care that may also be a risk for sleep disturbance: sources of potential selection bias and confounders (or possible mediators) of any relationship between caregiving and sleep that should be adjusted for in analyses. Second, to identify consistent and contrasting evidence about caregiver sleep disturbance, gaps in coverage and the potential contribution of this research. The chapter starts by outlining the measures of caregiving and sleep disturbance included in the review, below. It then details the literature review process in section 3.2. This is followed by an overview of what is known about the demographic, socioeconomic and health characteristics of caregivers in section 3.3, and the determinants of sleep disturbance in section 3.4. Section 3.5 reviews the literature on caregiver sleep, addressing general care provision in 3.5.2, relationship, location and hours of care in 3.5.3, caregiving transitions and duration in 3.5.4, partner characteristics in 3.5.5 and evidence of caregiving and sleep disturbance during the COVID-19 pandemic in 3.5.6. The research gap identified by the literature review is outlined in 3.6.

3.1.1 Measures of unpaid care and sleep disturbance included in the literature review

While measures of unpaid care rarely include care by a parent to a healthy child, some include care for a grandchild and for children who have a disability (Vlachantoni, 2010). Such care may be quite different in tasks and quality to unpaid care for an adult. For instance, grandchild care may involve help with homework (Di Gessa, Zaninotto, & Glaser, 2020) and has been associated with neutral (Danielsbacka, Tanskanen, Coall, & Jokela, 2019) or positive benefits to health (Di Gessa, Glaser, & Tinker, 2015). The focus of this thesis is on mid- and later life adults who provide unpaid care and support for adults. Wide-ranging measures of caregiving are used in the literature, often dependent on the available survey questions (Rutherford & Bu, 2018). Measures encompassing

differing quantifications of care in intensity of hours, numbers of tasks or frequency per week; relationships to the care recipient (differing generations and kin or non-kin relationships); and locations of care provision within or outside the home are all included in this review. Analysis incorporating different measures of caregiving builds knowledge of the implications of differing circumstances of caregiving (Arber & Ginn, 1990; Bom & Stöckel, 2021). The operationalisation of unpaid care characteristics used in this thesis is outlined in Methodology section 5.3.

As noted in Background section 2.4, there is no accepted definition of sleep disturbance and the terms sleep disturbance, sleep quality, sleep problems are sometimes used interchangeably in the literature without being defined (Peng & Chang, 2013). Therefore, while only subjective measurements are available in the data used in this thesis, the literature review includes evidence from analyses using subjective and objective measurements of sleep disturbance, sleep quality and sleep problems of differing definitions. To avoid confusion, the terms poor sleep and disturbed sleep are used, unless the exact definition from the study concerned is helpful, in which case this is included.

3.2 LITERATURE REVIEW PROCESS

There were two parts to the literature review. The primary purpose was to review the existing literature on how caregiving is associated with sleep disturbance. A secondary purpose was to identify the demographic, socioeconomic and health factors associated with provision of unpaid care, and those identified as risk factors for sleep disturbance; variables which may confound relationships between caregiving and sleep disturbance. Searches were conducted using the Web of Science (both searches) and Proquest databases (caregiver sleep search) and periodically updated. The searches were supplemented with articles found throughout doctoral study from reference lists, collections of academic research, citation searches of key articles and from email bulletins provided by peer-reviewed journals. Search terms for the two parts of the literature review are shown in Tables 3.1 and 3.2. Search terms for the review of factors

associated with care provision and sleep disturbance included geographical limitation to European or North American contexts.

Figures 3.1 and 3.2 present search results. The caregiver sleep search was conducted using two databases and duplicate articles were removed as a first step. Both searches then followed the same process to remove irrelevant articles. Articles were initially screened by title, then by abstract and last, by a reading of the full text. For the caregiver sleep search, the final articles were summarised in tabular format, Appendix A. Studies were included in the caregiver sleep review if sleep was a main outcome, unpaid care was provided by and to adults and the study included a non-caregiving control group (exceptions to this discussed below). Exclusion criteria included articles not written in English, meeting or conference abstracts, intervention studies and studies not including multivariable analysis. Qualitative research studies and previous reviews of the literature were read, and reference lists checked. As noted above, studies without a non-caregiving control group were excluded, except where limited other evidence was available. For instance, there were only a handful of cross-sectional population-based studies addressing caregiving duration and sleep. Studies with no non-caregiving controls were therefore included in the evidence assessed (for instance, Simon, Bueno, Otero, Blanco, & Vazquez, 2019). Studies without comparison to non-caregivers were also included when assessing the importance of partner health and studies using data collected during the COVID-19 pandemic, for the same reason.

Table 3.1 Search terms, identification of confounding factors

Title	OR	OR	OR	OR	OR	
OR	sleep caregiv*	insomnia care-giv*	carer*	"unpaid care"	"informal care"	
Abstract						
AND	demograph*	health	work	socioecono*	determinant*	
AND	England	UK	"United Kingdom"	US	"United States"	Europe
NOT	"young person"	adolescent				

Notes: articles from this search are presented in section 3.3 on factors related to unpaid care and section 3.4 on factors related to sleep disturbance

Figure 3.1: Search results, identification of confounding factors

Search terms: Title (sleep OR insomnia OR caregiv* OR care-giv* OR carer* OR "unpaid care" OR "informal care") AND
 Abstract (demograph* OR health OR work OR socioecono* OR determinant*) AND
 (England OR UK OR "United Kingdom" OR US OR "United States" OR Europe) NOT
 ("young person" OR adolescent*)

Articles in English, Web of Science: 2,704

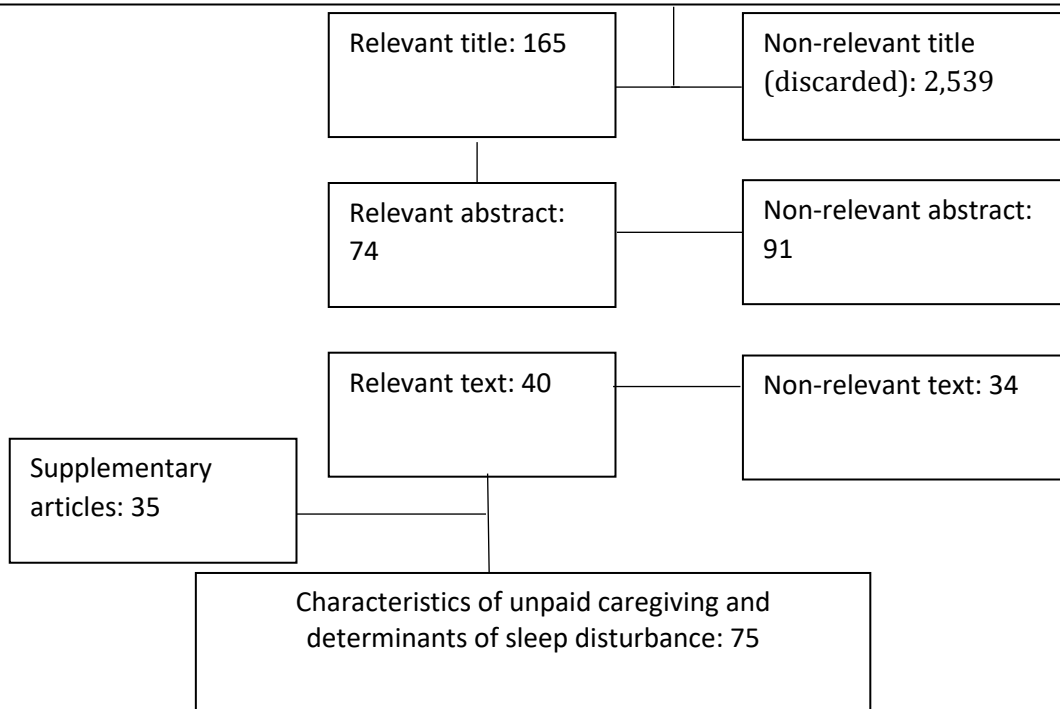
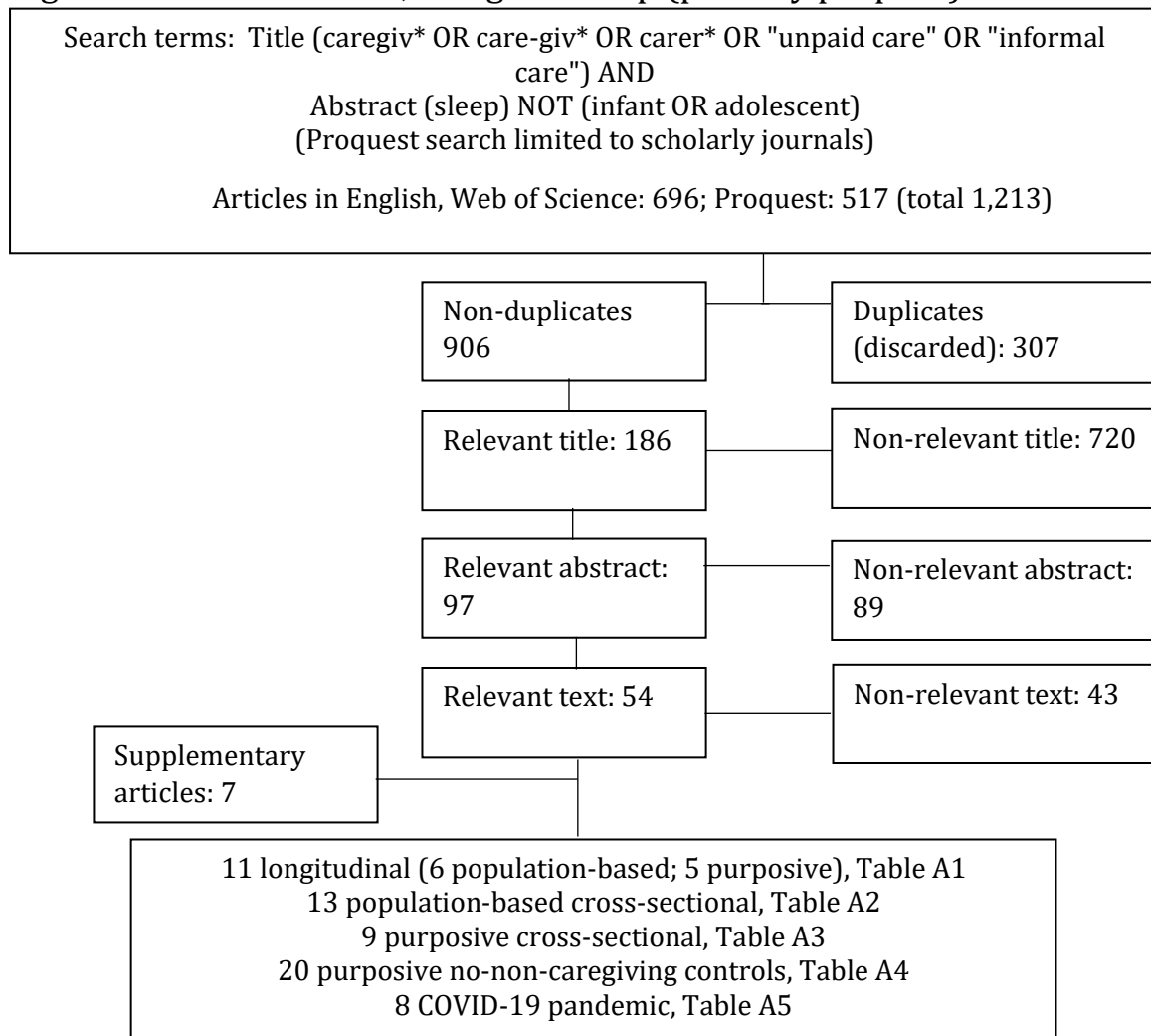


Table 3.2 Search terms, caregiver sleep (primary purpose)

Title	OR	OR	OR	OR
caregiv*	care-giv*	carer*	"unpaid care"	"informal care"
Abstract				
AND	sleep			
NOT	infant	adolescent		

Notes: articles from this search are presented in the main literature review on caregiver sleep, section 3.5

Figure 3.2 Search results, caregiver sleep (primary purpose)



3.3 DEMOGRAPHIC, SOCIOECONOMIC AND HEALTH FACTORS ASSOCIATED WITH UNPAID CARE

This section discusses factors related to unpaid care drawing on articles found in the literature search detailed in Table 3.1 and Figure 3.1. An estimated 65% of the adult population in the UK are likely to provide care over their lifetime (Zhang et al., 2019), approximately 17% in 2019 (Ashford & Hill, 2020). However, most individuals provide relatively few hours of care per week and the prevalence of different types and intensity of care differs across social stratifications (Arber & Ginn, 1995). Many factors may influence an individual's ability and motivation to provide unpaid care including societal expectations, individual attitudes and beliefs, trade-offs with undertaking paid work, availability of, and access to, alternative sources of care and differences in health (Al-Janabi, Carmichael, & Oyeboode, 2018; Carmichael & Ercolani, 2016; de Klerk, de Boer, & Plaisier, 2021; de Zwart et al., 2017; van Groenou & De Boer, 2016). Sociocultural and economic differences among men and women are important dimensions, and play a role in differing prevalence of caregiving among women and men across the life course, and gendered experiences of care (Arbel, Bingham, & Dawson, 2019; Bertogg & Strauss, 2020). This section discusses factors associated with unpaid caregiving and possible influences on likelihood of becoming an unpaid caregiver. These important potential confounding factors and sources of selection bias are important to address in the analyses in subsequent chapters of the thesis, see Methodology section 5.4. The section first addresses demographic characteristics, then socioeconomic characteristics and finally, health.

Demographic characteristics including the gender, marital status and age of the caregiver are important determinants of different forms of care provision, evidenced by results from studies analysing European and UK population-based survey data, for instance European Social Survey data (Verbakel et al., 2017) and British Household Panel Survey (Mentzakis, McNamee, & Ryan, 2009). Care provision is most likely during an individual's forties and fifties (Verbakel et al., 2017) when older parents and parents-in-law may start to require support (Arber & Ginn, 1995). At older ages, care for a spouse, partner, and other relationships, and for more than 50 hours per week increases in prevalence (Arber & Ginn, 1995; Vlachantoni, 2010). Women provide more

unpaid care than men in all but the oldest age groups (Dahlberg, Demack, & Bambra, 2007; de Klerk et al., 2021; Del Bono et al., 2009; Robards, Vlachantoni, Evandrou, & Falkingham, 2015), however, distinct differences in the patterns of informal care are found by gender. Men are most likely to provide care at older ages (Del Bono et al., 2009; Robards et al., 2015) and for a spouse or partner (de Klerk et al., 2021); while women provide more care in middle age (Del Bono et al., 2009; Robards et al., 2015), outside the home (Arber & Ginn, 1995; De Koker, 2009) and for parents and non-kin as well as spouses (de Klerk et al., 2021; Pickard, 2015). After the age of 65, while a higher proportion of men provide care than women (Dahlberg et al., 2007), this can be explained by differences in marital status and care provision. Men and women are equally likely to provide care to a spouse with care needs (Del Bono et al., 2009), however at older ages, more men are married than women, and widowhood is more common among older women than men (Office for National Statistics, 2018; 2020b). Once marital status is taken into account, women provide more care and more hours of care as they are more likely to live with a spouse with care needs or to provide care outside the home if widowed or single (Del Bono et al., 2009). Regarding hours of care, unlike care for parents or parents-in-law, for whom men provide fewer hours of care than women (Arber & Ginn, 1995), no gender differences have been found in hours of spouse care, irrespective of level of spouse need (Arber & Ginn, 1995; Langner & Furstenberg, 2020). Although few differences have been found in personal care among male and female spouse caregivers (Arber & Ginn, 1995), women provide more personal care to parents and parents-in-law. Most care to parents involves shopping, transport or the management of finances (McMunn, Lacey, & Webb, 2020). Wider gender norms may still be prevalent however, even where differences in care provision are slim, women undertake more general housework among older spouses (Langner & Furstenberg, 2020). Data from the annual Health Survey for England, HSE, indicates average care duration increases with age of the caregiver and over a quarter of caregivers aged 45 to 64 report caring for ten or more years (Ashford & Hill, 2020). Care over such a long period is more likely among mid-life married individuals (Robards et al., 2015) and could include care for one individual with long-term care needs, or for multiple individuals sequentially, for instance parent then spouse (Keating, Eales, Funk, Fast, & Min, 2019). Household size and the presence of children can also be important in decisions to provide unpaid care. Using dynamic random effects panel

models, Mentzakis and colleagues (2009) found larger household size increased the likelihood of women providing co-resident care, while the presence of young children decreased the likelihood; potentially indicating differences in need for care and time constraints (Mentzakis et al., 2009).

Differences have been found in unpaid care provision by socioeconomic status including wealth, income, education and work status, varying by measure, amount or type of care and by context (Agree & Glaser, 2009). Where care provision has been linked to better socioeconomic status, the definition of unpaid care is dominated by low intensity care. Care that can be considered more intense or challenging is most often linked to lower socioeconomic status. For instance, European women who finished secondary or tertiary education were more likely to provide informal care, dominated by non-resident care of a few hours per week, compared to those with lower qualifications (Verbakel et al., 2017). In contrast, findings from the Survey for Health and Retirement in Europe (SHARE) and the English Longitudinal Study of Ageing (ELSA) show that higher hours of care have been associated with fewer years of education (Waring, 2021), while co-resident care, considered likely to be more burdensome, is associated with lower wealth and incomes below the median compared to not providing such care (Quashie, Wagner, Verbakel, & Deindl, 2021). Associations between lower socioeconomic status by housing, education and social class, with spouse care and care of 20 or more hours per week, have been found using a variety of English data sources (Glaser & Grundy, 2002; Harris et al., 2020; Robards et al., 2015). These studies predominantly drew on cross-sectional data and cannot rule out reverse causality, such that care provision may lead to lower income, as may be the case where beginning to provide unpaid care leads to reduction in or cessation of work (Quashie et al., 2021). Indeed, the relationship between paid work and care provision is complex as “caregiving and employment histories evolve together and are intertwined over life-courses” (Carmichael & Ercolani, 2016). Analysis of 20 years of Longitudinal Study, LS, data, based on the Censuses of 1981 and 2001, revealed men who were unmarried or had seldom been in work in the previous 20 years were more likely to provide care for 20 hours per week (Young & Grundy, 2008). The same study indicated women were less likely than men to combine work and caregiving in general (Young, H. & Grundy,

2008), as found in other more recent studies (Carmichael & Ercolani, 2016). However, women working part-time or full-time were equally likely to provide care, possibly explained by societal expectations or socioeconomic pressures (Young & Grundy, 2008). Associations may also vary by the type of care and availability of alternative sources of care, for instance, women working part-time may be more likely to provide parent care than those working full-time (McMunn et al., 2020) and when providing non-resident care (Carr et al., 2016). Among men, a long full time work history has been linked to providing care for a parent (McMunn et al., 2020). Ability to, or necessity to, combine work and care may also be important: part-time or shift work has been associated with caring for 20 or more hours per week (Harris et al., 2020). In general, being out of paid employment, whether retired, undertaking housework or being unemployed are all associated with providing any care (Verbakel et al., 2017) and co-resident care (Quashie et al., 2021), the relationship strengthening with greater intensity of care provision (Verbakel et al., 2017).

The potential health consequences of unpaid caregiving are the subject of considerable research, briefly discussed in Background section 2.3. Far fewer studies address how health influences the probability of caregiving (de Klerk et al., 2021; Scharn et al., 2019), though evidence can be drawn from some investigations of caregiver health (de Zwart et al., 2017; Kaschowitz & Brandt, 2017; Ramsay et al., 2013). Group differences between those who go on to become caregivers and those who do not has been argued as a possible reason for contrasting results found among some studies of caregiver health and mortality (Ramsay et al., 2013). In relation to group differences, the direction of differences is the subject of debate. Some suggest individuals in poorer health may be more likely to take up care where health precludes paid work but increases their availability to provide care (for instance, de Zwart et al., 2017). Others assert that healthier individuals are more likely to undertake unpaid care and to benefit from the greater physical activity and mental agility required from unpaid care tasks, the healthy caregiver hypothesis (Fredman et al., 2010). Further, unhealthier caregivers may be more likely to die prior to follow up measurements, survivor bias (Glaser, Evandrou, & Tomassini, 2005). There is little evidence in support of the healthy caregiver hypothesis. Rather differences in initial health of caregivers compared to non-

caregivers have often differed by sub-group of caregiver, reinforcing the need to account for group differences and caregiver heterogeneity in analyses (Mehri et al., 2019; Ramsay et al., 2013). Health differences have indeed been found between those not providing care and caregivers. For instance, analysis of Longitudinal Study data indicated reporting limiting long term illness and poor self-rated health (SRH) was more likely among caregivers than non-caregivers at baseline in 2001, yet the study found evidence of a subsequent mortality advantage for unpaid care provision after a period of eight years (Ramsay et al., 2013). Whether health is important to becoming a caregiver may vary by relationship of care. Cross sectional analysis of ELSA data found differences in self-rated health and limiting illness did not affect the odds of being a “round the clock” care provider (168 or more hours per week), mostly undertaken by spouses at older ages (Vlachantoni, 2010). Similarly, analysis from the Netherlands, found that spouse care was not influenced by serious obstacles faced due to a long-standing health problem, but reduced the likelihood of providing care for other relatives (de Klerk et al., 2021). Advanced statistical methodologies which attempt to address possible selection into caregiving, in part or completely, are increasingly common. These include the instrumental variable approach, propensity score matching and fixed effects models. For instance, longitudinal studies have found spouses who go on to provide care are more likely to exhibit health risk behaviours such as not getting enough rest or not going to the doctor when needed (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003) and have a higher probability of prescription drug use than those who never go on to provide spouse care (de Zwart et al., 2017), though neither study found differences in SRH. Similarly, individuals providing co-resident care have been found to be more likely to have poorer SRH (Kaschowitz & Brandt, 2017) and poorer mental health, measured by the General Health Questionnaire (Mentzakis et al., 2009). There are several possible explanations for poor health selecting individuals into spouse and co-resident care. Spouse care may be carried out despite major health difficulties, as a necessity, or as a fulfilment of marital commitment (de Klerk et al., 2021). Poorer health that precludes working may instead allow time and increase pressure to provide care (de Zwart et al., 2017). Additionally, poor health among those going on to provide spouse care may be indicative of similarities in health among couples through a lifetime of shared socioeconomic resources and common environments (Kaschowitz & Brandt, 2017). Studies have found differing patterns for non-resident care. For instance,

Kaschowitz and colleagues (2017) in the study above further concluded individuals with better self-rated health (SRH) were more likely to take up non-resident care provision. However, a second study using similar SHARE data with one additional wave found both having, and onset of, a chronic disease increased the relative risk of non-resident care provision (Scharn et al., 2019). It may be that the broad definition of chronic disease adopted in the latter study included individuals who self-assessed their health as good, though they had or developed a chronic disease. Further, experience of chronic disease may offer motivation to provide care to others through experience of care management or navigating the care system (Scharn et al., 2019). These diverse ways in which health may influence care provision may be hidden when general definitions of care are used, where factors related to the obligation to care (such as age of spouse or having a lone older parent), as well as gender or being in paid work, discussed previously, may be more important (Bom & Stöckel, 2021). Collectively, these findings indicate both physical and mental health may be important factors in determining whether individuals undertake unpaid care, though varying in influence by the measure of health used and the characteristics of care provision. These demographic, socioeconomic and health factors are important to address as possible confounders (or mediators) and sources of selection bias in the analyses in this thesis. This requires methods which can account for differences between individuals, see Methodology section 5.4. The next section addresses similar risk factors for sleep disturbance.

3.4 RISK FACTORS FOR SLEEP DISTURBANCE

This section reviews the literature on risk factors for sleep disturbance, focusing on factors available in datasets such as ELSA (Table 3.1 and Figure 3.1 provide search details). Shared risks of sleep disturbance and becoming an unpaid caregiver are important to include in analyses of caregiver sleep to reduce confounding and allow identification of associations that may be independently attributable to caregiving characteristics. As for caregiving in section 3.3, demographic, then socioeconomic factors are reviewed, then health factors associated with sleep disturbance.

Objectively measured sleep among healthy adults changes with age, in complex ways. A landmark meta-analysis assessing objectively measured sleep found increases in sleep disturbances and changes in sleep architecture as age increased; though after the age of 60, fewer changes were observed (Ohayon, Carskadon, Guilleminault, & Vitiello, 2004). Changes associated with normal aging include increasing sleep fragmentation, lighter, less restorative sleep and earlier awakening (Vaz Fragoso & Gill, 2007). Similarly, subjectively measured sleep disturbance has been found to increase from early adulthood until the age of 60, while sleep quality decreases (Grandner et al., 2012; Lemola & Richter, 2012). However, except for a short window of improved sleep quality among adults in their early sixties, coinciding with retirement for some (Lemola & Richter, 2012), sleep quality may be relatively stable after the age of 60 (Grandner et al., 2012; Lemola & Richter, 2012). Nevertheless, older adults may assume their sleep will be poorer in later life (Gibson et al., 2014; Venn & Arber, 2012) and this may be linked to age-related health changes, discussed further below (Smagula, Stone, Fabio, & Cauley, 2016). Gender differences in self-perceived sleep disturbance are well evidenced (Arber, Bote, & Meadows, 2009; Fatima et al., 2020; Lallukka et al., 2012; van de Straat & Bracke, 2015). Women self-report more disturbed sleep than men, particularly in mid-life, with differences no longer apparent after the age of 70 (Grandner et al., 2012). However, women may underestimate the quality of their sleep compared to objective measures, while men may underestimate objectively poorer sleep (Della Monica, Johnsen, Atzori, Groeger, & Dijk, 2018). Non-white ethnicity is also linked to poorer sleep (Grandner et al., 2012), but not analysed in this thesis as ELSA ethnicity data contains high levels of missingness and the number of individuals reporting being non-white is small. Close social relationships and their quality have been found important for sleep quality (Troxel, Robles, Hall, & Buysse, 2007). For instance, being married or in a similar partnership has consistently been associated with better sleep, compared to being widowed (Lallukka et al., 2012; van de Straat & Bracke, 2015), separated or divorced (Arber et al., 2009; Grandner et al., 2010; van de Straat & Bracke, 2015) or single (Grandner et al., 2010). Among the married, marital satisfaction may be important for sleep (Chen, Waite, & Lauderdale, 2015; Troxel et al., 2007). Household indicators may also be important. For instance, a higher number of household occupants has been associated with restless sleep among adults aged 41 to 64 (Chapman et al., 2012); while presence of children in a household has been

associated with both worse (Chapman et al., 2012) and better sleep (Lallukka et al., 2012).

Lower socioeconomic status has also been linked to greater sleep disturbance across measures including income, wealth, education and work status (Arber et al., 2009; Dregan & Armstrong, 2011; Fatima et al., 2020; Grandner et al., 2012; van de Straat & Bracke, 2015). For instance, among women and men aged 50 and over in Europe, higher wealth, indicative of lifetime socioeconomic status (Brandt, Kaschowitz, & Quashie, 2021), was associated with decreased trouble sleeping overall, and among women but not men (van de Straat & Bracke, 2015). Studies including more than one measure of socioeconomic status have found differing results depending on the measure used. For instance, Arber and colleagues (2009) found secondary level or lower education and unemployment or economic inactivity were associated with frequent sleep problems after adjustment for psychological and physical health and worries, while an association with housing problems was explained by worries. The authors considered that difficulties and distress caused by structural disadvantages of lower socioeconomic status (for instance, poor quality housing with thin walls) as possible mechanisms driving these patterns (Arber et al., 2009). There is a large literature devoted to the characteristics of work associated with poorer sleep, for instance, roles working against circadian rhythms such as shift work (Fatima et al., 2020) and jobs with high levels of stress (Dregan & Armstrong, 2011). Among more general studies of those in and outside the labour market, paid work has been linked to better sleep than being retired (van de Straat & Bracke, 2015) or unemployed (Blanchflower & Bryson, 2021; Palmer et al., 2017) and not being able to work due to sickness or disability (Blanchflower & Bryson, 2021; van de Straat & Bracke, 2015). However, the transition to retirement itself among adults in paid work is associated with improvements in sleep quality (Lemola & Richter, 2012) and decreasing sleep disturbance (van de Straat, Platts, Vahtera, Westerlund, & Bracke, 2019), which may be due to reductions in work related stress and increased opportunities to manage commitments within daytime hours (van de Straat et al., 2019).

In addition to normal age-related sleep changes, health changes, such as reductions in function and increasing occurrence of chronic disease, can also disrupt sleep (Vaz Fragoso & Gill, 2007). These health-related sleep disturbances can occur due to pain or side-effects of medication (Vaz Fragoso & Gill, 2007). In epidemiological studies, limiting illness and self-rated health are often strongly correlated with sleep disturbance (Dregan & Armstrong, 2011; Fatima et al., 2020; Grandner et al., 2012). Many of the relationships between sleep and health are considered complex and show evidence of bidirectionality as noted in Background section 2.4. For instance, findings from the German socioeconomic panel show that self-rated health and sleep quality were each predictive of the other across four years (Lemola & Richter, 2012). Considering particular conditions, chronic health conditions can disturb sleep due to physical night time symptoms, medical side effects, pain or distress (Foley, Ancoli-Israel, Britz, & Walsh, 2004; Ohayon, 2005; Poole & Jackowska, 2018). For instance, in mutually adjusted models (including age, sex, marital and socioeconomic status), lung disease, depression, angina, arthritis and asthma were consistently associated with severe sleep problems in nine countries, including within Europe: Finland, Spain and Poland (Koyanagi et al., 2014). Some of these conditions have common causes, and many individuals have multiple morbidities, nevertheless, a dose-response relationship between number of chronic conditions and severe sleep problems was found (Koyanagi et al., 2014). Sleep problems are common symptoms of neurological disorders (Vaz Fragoso & Gill, 2007). For instance, one study found 53% of people with Alzheimer's disease had insomnia (Pistacchi et al., 2014), while motor symptoms causing abnormal movements can disrupt sleep in Parkinson's disease (Zahed et al., 2021). A significant possible symptom of several chronic conditions is the experience of pain. Chronic back, joint, limb and headache pain have been associated with individual symptoms of insomnia and the proportion of individuals reporting any pain increased with the number of insomnia symptoms reported (Ohayon, 2005). Lifestyle factors such as smoking, drinking alcohol and limited physical activity have also sometimes been related to sleep disturbance (Dregan & Armstrong, 2011; Fatima et al., 2020; Foley et al., 2004; Grandner et al., 2012; Poole & Jackowska, 2018; Tang et al., 2015). Psychological factors are common correlates of sleep disturbance (Knutson, 2013; Smagula et al., 2016). While sleep disturbance can increase the risk and persistence of depressive symptoms as noted in chapter two (Bao et al., 2017), major depressive episodes are

associated with the most common symptoms of insomnia (Ohayon, 2005) and high depressive symptoms at baseline have been associated with sleep disturbance four years subsequently (Poole & Jackowska, 2018). Social stressors have also been noted as significant risk factors for sleep disturbance, such as the experience of stress at work (Garefelt et al., 2020) and more general stressful life occurrences (Hall et al., 2015; Ohayon, 2005).

In relation to the COVID-19 pandemic, data from the UK and countries such as the United States and France indicated greater sleep disturbance in the initial months, dropping to lower levels in the latter half of 2020, among all adults (Falkingham, Evandrou, Qin, & Vlachantoni, 2022; Morin et al., 2021). Changes in sleep may be related to differing individual circumstances and exposure to pandemic stressors (Robillard et al., 2021; Wright et al., 2021). Experiencing more pandemic-related worries, stressors or adversity has been associated with sleep disturbance, poorer sleep quality and high symptoms of insomnia (Wen, Klaiber, DeLongis, Slavish, & Sin, 2021; Wright et al., 2021). Health-related stressors related to poor sleep include being clinically extremely vulnerable to COVID-19, fearing infection or having had COVID-19, and having chronic conditions such as depression, arthritis and chronic obstructive pulmonary disease (Falkingham et al., 2022; French, Mortensen, & Timming, 2022; Morin et al., 2021; Polenick, Daniel, & Perbix, 2021; Steptoe & Steel, 2020; Udeh-Momoh et al., 2021; Wright et al., 2021). Living alone or with more than five people, poorer socioeconomic circumstances, being a woman, of younger age, and having family responsibilities, including caregiving, have been associated with increased sleep disturbance (Beach, Schulz, Donovan, & Rosland, 2021; Falkingham et al., 2022; Robillard et al., 2021; Wright et al., 2021). Black and minority ethnic groups also had poorer sleep, explained by greater likelihood of being a key worker and experiencing financial difficulty relative to white respondents in the UK (Falkingham et al., 2022). These reviews of important factors related to care provision and to sleep disturbance provide evidence of characteristics that should be accounted for in the multivariable analyses in the thesis investigating associations between caregiving and sleep disturbance. The next section reviews existing evidence of relationships between unpaid caregiving and sleep disturbance.

3.5 CAREGIVING AND SLEEP DISTURBANCE

3.5.1 Overview of caregiver sleep studies

In comparison to the wider caregiver health evidence base, the caregiver sleep literature is much smaller, with few longitudinal studies (literature search details in Table 3.2 and Figure 3.2). Caregiver sleep studies have predominantly focused on groups of caregivers of patient groups for whom sleep disturbance can be a symptom of their disease or of treatment, most often dementia or cancer (Byun et al., 2016). These studies tended to be small scale and rarely included non-caregiving controls, as study objectives often derived from an interest in improving clinical outcomes for patients and the experience of their caregivers (Byun et al., 2016). Non-caregiving controls are included in studies aiming to understand how caregiving is related to sleep, relative to individuals without care responsibilities. As sleep has become a more prominent outcome of interest for sociological and epidemiological enquiry (Ferrie et al., 2011; Williams, 2002), items on aspects of sleep have been included in large scale population-based studies such as ELSA and Understanding Society in the UK, the Survey for Health, Ageing and Retirement in Europe and the Health and Retirement Study in the United States (Arber & Meadows, 2011a). An increasing but small number of population-based cross-sectional and longitudinal studies of caregiver sleep have drawn on this data. Prior to 2017 only two longitudinal caregiver sleep studies including non-caregivers had been carried out, both on purposive samples of caregivers of people with dementia and matched controls (Rowe, McCrae, Campbell, Benito, & Cheng, 2008; von Kaenel, Mills et al., 2012) and one study without non-caregiving controls, included in the literature review as it incorporates partner health covariates (von Kaenel et al., 2014). Since 2017, eight further studies have been published, six of which used data representative of the population under investigation (DePasquale, Sliwinski, Zarit, Buxton, & Almeida, 2019; Gerlich & Wolbring, 2021; Hajek & Koenig, 2022; Maun, Glaser, & Corna, 2020; Sacco et al., 2018; Song et al., 2017; van de Straat, Willems, & Bracke, 2021; Virtanen et al., 2021). Appendix Table A1 lists the characteristics and key results for these 11 longitudinal studies. Thirteen population-based cross-sectional studies were found, eight studies including non-caregivers and three without non-caregiving comparison (Appendix Table A2). Most of these cross-sectional population-

based studies utilised survey data from Europe and the US; four drew on data from Brazil, New Zealand, South Korea and 58 countries participating in the World Health Survey. Nine studies were included in the review that drew on purposive samples which included non-caregiving controls (Appendix Table A3). These studies were predominantly from the US, sampling caregivers of people with dementia and matched controls. Until three studies were published in early 2022, very limited population-based research was found incorporating care duration or partner health characteristics as explanatory variables. Therefore, 20 small purposive studies without non-caregiving comparison were included in the review because they investigated partner health characteristics or care duration (Appendix Table A4). Finally, eight studies of caregiving and sleep including multivariable analysis were found utilising data collected during the COVID-19 pandemic (Appendix Table A5). Four included non-caregiving controls and one utilised longitudinal population-based SHARE data (Bergmann & Wagner, 2021). Gender differences in caregiving and sleep, either through stratified samples or interaction terms were included in 3 longitudinal studies and 3 cross-sectional studies. The review of these studies that follows begins by discussing studies using a general definition of caregiving, section 3.5.2. As discussed in Background section 2.3 and section 3.3, caregiver health studies have often found differences in health by caregiving characteristics. Therefore, caregiver sleep studies addressing these caregiving characteristics are reviewed in section 3.5.3 (location of care, relationship to the care recipient and caregiving hours) and section 3.5.4 (caregiving transitions and duration). Studies including analysis of care recipient and partner health are discussed in section 3.5.5 and what is known about caregiver sleep during the COVID-19 pandemic is reviewed in section 3.5.6.

3.5.2 General care provision

The studies in this section used a general definition of caregiving, without delineating caregiving hours, location, relationship between the care recipient and caregiver, or health characteristics of the care recipient. Two studies were longitudinal, each focusing on a working population: Finnish working adults (Virtanen et al., 2021) and women working in care homes (DePasquale et al., 2019). Seven studies were cross-sectional, mostly drawing on large population-based samples, including 58 countries

responding to the World Health Survey (Koyanagi et al., 2018), women veterans in the United States (Song et al., 2021) and a multi-State telephone survey in the United States and Puerto Rico (Liu et al., 2020; Trivedi et al., 2014). Each study found general care provision was associated with at least one measure of subjective sleep, except for a small study using a purposive sample where higher odds of sleep problems were found only among caregivers with high depressive symptoms (Kochar, Fredman, Stone, & Cauley, 2007). Among the longitudinal studies of working populations, care provision was associated with increased sleep disturbance among public sector workers (Virtanen et al., 2021) and poorer sleep quality and less time in bed among care home workers who also provided unpaid care to an adult (DePasquale et al., 2019). For instance, Virtanen and colleagues (2021) analysed two large Finnish datasets of working adults aged 50 and over, using fixed effects models. They found associations between informal caregiving and any sleep disturbances (measured using the Jenkins sleep problems scale), as well as specific sleep problems such as difficulty falling asleep and waking up early (Virtanen et al., 2021). They also found a higher level of control over work time (such as hours of work) reduced the odds of sleep disturbance among caregivers, indicating sleep disturbance may result from conflicting work and care responsibilities, alleviated by increased control over the timing of work (Virtanen et al., 2021). In this Finnish study, use of longitudinal data and fixed effects models enabled change to be modelled over time within individuals, removing time-constant differences between individuals. However, the study focused only on the working population. The cross-sectional studies found associations with severe sleep problems and caregivers in low-, middle- and high income countries (Koyanagi et al., 2018) and poor sleep due to stress among veteran caregivers (Song et al., 2021). Sleep duration was the focus in several studies from the United States, finding care provision associated with shorter sleep, measured as less than seven hours (Blinka et al., 2022; Flood & Moen, 2015; Liu et al., 2020) and inadequate sleep duration of less than 7 hours per night, or more than 9 hours per night (Trivedi et al., 2014). Most studies used subjective measurements and where clinically defined or objective measures were included, no associations were found (DePasquale et al., 2019; Song et al., 2021). For example, among US veterans, care provision was associated with perceived sleep disturbance due to stress but not with insomnia, measured by the insomnia severity index (Song et al., 2021). These studies including individuals within and outside of the labour market were all cross-sectional

and as a result the associations found may be attributable to unobserved or pre-existing differences between caregivers and non-caregivers. In addition, samples included all adults, masking significant heterogeneity at different life stages for instance, in the relationships of care and by gender, which may be important for interpreting results. For instance, Koyanagi and colleagues (2018) analysed associations between caregiving for an adult or child with long term mental health, physical health problems or disability and severe or extreme sleep problems with falling asleep, waking up frequently or too early, across all 58 countries. Specifically, among high income countries, increased odds of severe sleep problems were found among young adults (18 to 44) and older adults (65 and over), but not 45- to 64-year-olds (Koyanagi et al., 2018). Explanations noted included the likelihood of differing relationships of care and caregiving stressors at younger and older ages (Koyanagi et al., 2018). However, Koyanagi and colleagues (2018) also analysed care intensity, described in the next section. The analysis of caregiving by the circumstances of care and characteristics of the caregiver, such as relationship to the care recipient, location of care or quantifying the amount of care, may elicit more nuanced results.

3.5.3 Characteristics of caregiving: relationship to care recipient, location, and hours

Spouse care and co-resident care are often characterised as more stressful, often involving longer hours of care, with fewer opportunities to take a break, or socialise (Pinquart & Soerensen, 2011). Parent care and fewer hours of care per week, most often provided outside the home, may be combined with work (McMunn et al., 2020; Vlachantoni, 2010). In some studies, combining low levels of care and part-time work has been associated with physical health benefits (Bom & Stöckel, 2021). Few studies of caregiver sleep have addressed relationship or location of care. Relationship of the care recipient to the caregiver has mostly focused on spouse care, most studies having no non-caregiving controls (Mills et al., 2009; von Kaenel et al., 2014; Zhang, Yao, Yang, & Zhou, 2014). The strongest evidence from these studies comes from longitudinal analysis of caregivers of a spouse with Alzheimer's disease using random effects models and estimating within- and between- effects (von Kaenel et al., 2014). The study found within individual change in mood (positive and negative affect) were related to

subjectively measured sleep quality measured by the Pittsburgh Sleep Quality Index, PSQI, but not objective sleep measures (2014). In addition, increased sleep disturbance was associated with being female and having a partner with more and increasing problem behaviours (2014). Of the two studies including non-caregivers, neither found an association between care provision and sleep disturbance (von Kaenel, Mausbach et al., 2012; Willette-Murphy, Toderro, & Yeaworth, 2006). For instance, in longitudinal analysis, no relationship was found between spouse care and subjective and objective measures of sleep, but a positive association was found between depressive symptoms and subjectively perceived sleep quality (von Kaenel et al., 2012). The study used random effects models on data from the same study of spouse caregivers of people with Alzheimer's disease as discussed above, and used age and gender matched non-caregivers. The results of these studies are therefore not generalisable to other types of care situation. Only two studies addressed other types of care relationship. The first found both spouse and non-spouse care, in combination with high depressive symptoms, were associated with different aspects of sleep disturbance⁶ (Kochar et al., 2007). The second, found carrying out a greater number of medical or nursing tasks (as well as poorer relationship quality and being female) was associated with more care-related sleep disturbance among spouse caregivers but not caregivers to other relations or friends (Polenick, Leggett, Maust, & Kales, 2018). The authors indicated these tasks may be more stressful among spouses, but no comparison of sleep disturbance levels was made with non-caregivers.

The relationship of care recipient to the caregiver is closely related to the location of care, as most co-resident care is provided to a spouse, particularly among men, see section 3.3. Five population-based studies addressed care location (Arber & Meadows, 2011b; Blinka et al., 2022; Gibson, Gander, Alpass, & Stephens, 2015; Song & Kim, 2021), one using longitudinal data (Maun et al., 2020). Two purposive samples (Simpson & Carter, 2015), one including non-caregiving controls were also found (Kochar et al., 2007). The available evidence is mixed from these studies. Co-resident care but not non-resident care was associated with problematic sleep in a UK context, drawn from

⁶ Spouse caregivers had greater trouble staying asleep and waking early than non-caregivers; non-spouse caregivers had more trouble going to sleep

longitudinal (Maun et al., 2020) and cross-sectional analysis of the UK Household Longitudinal Study (Arber & Meadows, 2011b). This was also the case in a small purposive study, but only among individuals who all had high depressive symptoms (Kochar et al., 2007). However, no association was found with short sleep, measured as less than 7 hours per night, in the US (Blinka et al., 2022), or with dissatisfaction with sleep in New Zealand (Gibson et al., 2015). In the latter study, caregivers were more likely to be women, live in deprived areas and be Maori, characteristics that were associated with dissatisfied sleep (Gibson et al., 2015). When care provision to people with dementia has been the focus, an association between caregiving and poor sleep was unexpectedly not altered by care location in both a small scale (Simpson & Carter, 2015) and a large-scale study⁷ (Song & Kim, 2021). For instance, cross-sectional analysis of representative Korean data found both co-resident and non-resident caregivers of people with dementia were more likely to have a PSQI score of more than 5 compared to non-caregivers (Song & Kim, 2021). Sleep disturbance associated with non-resident care provision may be due to worries about a non-resident relative or night-time confused or distressed phone calls (Simpson & Carter, 2015). The Korean study adjusted for a wide range of health factors including depressive symptoms and perceived stress; factors that have explained associations between care provision and sleep disturbance in some other studies. However, this latter study was cross-sectional and carried out in a different cultural context. In addition, most studies were cross-sectional and did not fully account for possible pre-existing differences in sleep between non-caregivers and caregivers by location. A gap exists to address care recipient relationship to the caregiver and location of care with longitudinal population-based analysis, comprehensive adjustment for confounders and addressing potentially omitted variables.

Studies quantifying the amount of care in relation to sleep disturbance are more numerous and have addressed care of differing intensities, frequencies, and number of tasks. Two studies defined care intensity by the number of care activities. In the multi-country study described in section 3.5.2 above, higher odds of sleep problems were also

⁷ The study included 2,537 co-resident caregivers of people with dementia, 8,864 non-resident caregivers of people with dementia and 190,278 non-caregivers.

found with increasing care tasks, up to a total of five, including personal care, supervision and household activities (Koyanagi et al., 2018). In contrast, among older female spouses (mean age 82, standard deviation 4), no differences were found in subjective sleep quality (PSQI) or actigraphy-measured wake after sleep onset between non-caregivers and high or low intensity caregivers, measured by number of ADL's and IADL's supported (Song et al., 2017). However, among high intensity caregivers, those reporting high perceived stress had greater wake after sleep onset than high intensity caregivers reporting low stress (Song et al., 2017). Sleep was measured once in both studies and pre-existing sleep differences cannot be excluded in explanations of the study results. Higher care intensity, measured by hours per week, has also been associated with sleep disturbance. Co-resident care of 20 or more hours per week has been associated with two or more sleep problems (Maun et al., 2020), and 20 or more hours of any care per week with shorter sleep duration (Liu et al., 2020). The latter study used data from the Behavioural Risk Factor Surveillance System, an annual cross-sectional health and health behaviours survey in the US. Five years of pooled data from the same survey has recently been used to analyse caregiving hours, measured continuously, also finding higher odds of short sleep (Secinti et al., 2022). Among all adults however, a relationship between shorter caregiving hours and sleep has sometimes been found. For instance, gender-stratified analysis of adults aged over 25 years in the UK indicated associations among women between providing co-resident care for 1 to 20 hours per week and for 100 or more hours per week and two or more sleep problems (Arber & Meadows, 2011b). Poorer self-rated health and limiting illness explained associations found among women caregiving 21-99 hours per week, while among men, unemployment, retirement, or disability explained associations with care of 20 or more hours per week (Arber & Meadows, 2011b). Shorter hours of care provision have also been associated with sleep disturbance among employed adults providing more than 5 hours of care per week (Sacco et al., 2018). Combining shorter hours of care with raising children (Arber & Meadows, 2011b) or balancing care with paid work may have led to conflicting demands and stress-related sleep disturbance (Sacco et al., 2018), for instance, due to lack of control over timing of work (Virtanen et al., 2021). Difficulty in combining paid work and care, even with greater availability of state-supplied services, may be indicated by the low levels of care provision in the Swedish sample: only 1.2% of the sample provided care for 6-10 hours per week and

0.7% for more than 10 hours per week (Sacco et al., 2018). Ten hours of care per week is the threshold found by some studies to be associated with a greater likelihood of exiting paid work (Carr et al., 2016; King & Pickard, 2013). Analysis of transitions, and particularly a reduction in sleep disturbance with cessation of care in the sample of Swedish workers, discussed in the next section, supports an interpretation of stress-related sleep disturbance (Sacco et al., 2018). The review of characteristics of care associated with sleep disturbance demonstrates a clear gap in our understanding related to the role of the relationship of care recipient to caregiver and the location of care. The existing literature on care intensity is limited as most work is cross-sectional and cannot distinguish between pre-existing differences in sleep disturbance and those associated with changes in unpaid care. Several of the longitudinal studies focus on subgroups of the population: US veterans and working adults, and results may not be inferred to the wider population. For instance, including adults who are in and out of the labour market is important as section 3.4 highlighted individuals working and caring are more likely to provide shorter hours of care, non-resident care and parent care. Analysis of those individuals both within and outside the labour market allows investigation of the full range of caregiving situations to be analysed, particularly the growing number of older retired caregivers.

3.5.4 Care transitions and duration

Available longitudinal data allows the exploration of sleep at different points in a care trajectory and by duration of care provision. Six longitudinal studies have been published assessing care transitions and sleep. Studies of Swedish working adults (Sacco et al., 2018), UK adults over 65 years old (Maun et al., 2020) and caregivers of people with Alzheimer's disease (von Kaenel et al., 2012) were introduced earlier in the review. In addition, two studies addressed mid- and late life adults (Hajek & Koenig, 2022; van de Straat et al., 2021) and one, older spouse caregivers (Gerlich & Wolbring, 2021). Of these studies, the first used Deutscher Alterssurvey, DEAS, data, and fixed effects models to investigate starting and ceasing regular care due to poor health and three single sleep measures: difficulty falling asleep, waking up early and overall sleep quality (Hajek & Koenig, 2022). The second used five waves of SHARE data and random effects models to investigate caregiving transitions and trouble sleeping among adults

aged 50 and over (van de Straat et al., 2021). The third study used nine years of German panel data, fixed effect models with impact function for each transition and analysed satisfaction with sleep (a domain of life satisfaction) as a sub-analysis to the main study (Gerlich & Wolbring, 2021). The only study to find evidence of trouble sleep at each transition and period of continuous care was the study of European data using random effects, which found highest odds of trouble sleeping at the start of care provision and lowest odds when care ceased (van de Straat et al., 2021). All studies found some evidence of increased sleep difficulties among caregivers; consistently so for individuals providing care over two consecutive waves, equating to two or three years (Maun et al., 2020; Sacco et al., 2018; van de Straat et al., 2021). However discrepant results were found at the beginning and end of care provision and by gender. For instance, women and men aged 50 and over starting to provide daily care were found to have increased odds of trouble sleeping (van de Straat et al., 2021). In other studies, an association between starting care and sleep disturbance was found only among men (Hajek & Koenig, 2022), or not at all (Gerlich & Wolbring, 2021; Maun et al., 2020; Sacco et al., 2018). Similarly, inconsistent results were found for care cessation. Sleep disturbance has been linked to ceasing care among mid- and late life adults (van de Straat et al., 2021) and bereaved caregivers of people with Alzheimer's disease (von Kaenel et al., 2012) and more generally . However, evidence is equivocal as some studies have found no association (Hajek & Koenig, 2022; Maun et al., 2020; von Kaenel et al., 2012), while others differed by the reason for cessation of care. Von Kaenel and colleagues (2012) found no differences in sleep among caregivers for a person with Alzheimer's disease who moved into an institution, while those whose spouse died had shorter objectively measured night-time sleep and longer waking time at night. As the authors indicated, moving a spouse into an institution may involve a mixture of emotions and care may continue in a different form (von Kaenel et al., 2012). Indeed, a third of caregivers whose family member was in a hospice reported sleep disturbance in one study (Washington et al., 2018). Similar results were found among more general spouse caregivers: bereavement but not recovery was associated with lower satisfaction with sleep initially and up to three years after death (Gerlich & Wolbring, 2021). However, their fixed effects models only controlled for age (2021). Other time-varying confounders such changing financial, or health circumstances may be important to include in analyses of sleep, particularly after widowhood (Kaufman, Lee, Vaughn,

Unuigbe, & Gallo, 2019). Among working adults in Sweden, ceasing care reduced sleep disturbance, though not to the level found when not providing care, possibly in response to reduced difficulties in balancing care and work commitments (Sacco et al., 2018). Gender differences were also inconsistent where analysed. In the Swedish working population, higher sleep disturbance was found among men providing care of five or more hours with little difference among women (Sacco et al., 2018). Studies of mid- and late-life adults found no gender differences except for when starting to provide care. In the German study, men but not women had lower sleep quality and greater difficulty waking up when starting to provide regular care (Hajek & Koenig, 2022); contrasting with the study of European countries which found women starting to provide daily care had significantly higher odds of trouble sleeping than men (van de Straat et al., 2021).

While the studies above provide some evidence of associations between care duration and sleep disturbance through estimates of continued care across two consecutive waves, care duration in number of years has also been analysed. In the broader population-based caregiver health literature evidence of an association between longer care duration and poorer mental health has been mixed (Capistrant, Berkman, & Glymour, 2014; Lacey, McMunn, & Webb, 2018; Stöckel & Bom, 2022). Several recent population-based studies, all from the United States and briefly introduced above, have incorporated care duration. Two studies found no association between care duration measured continuously and sleep duration or sleep quality. Both studies analysed caregivers only and adjusted for a variety of caregiving characteristics (Blinka et al., 2022; Secinti et al., 2022). For instance, in analysis of five years of telephone health survey data, caregiving duration was not found to be associated with short sleep duration, though caregiving hours and personal care were, as detailed above (Secinti et al., 2022). However, similar analysis of one year of the same survey data found caregivers providing five or more years of care were more likely to sleep for less than seven hours per night than individuals caregiving for less than two years (Liu et al., 2020). Small studies (respectively N=201 and N=134) drawing samples from a Spanish registry of caregivers of dependent individuals have also found contrasting results. The first found caregivers of people with dementia who provided care for a longer duration

(more than 8 years) had higher odds of insomnia than those caring for 8 or less years (Simon et al., 2019). The same authors did not find an association between care duration and sleep quality (measured by PSQI) among a sample of co-resident caregivers (Simon, Bueno, Blanco, Otero, & Vázquez, 2022). Caregiver burden and poorer mental health were the only significant explanatory factors in the latter analysis (Simon et al., 2022), not added as controls in the first exploratory study (Simon et al., 2019). The review indicates that care duration has until recently been overlooked in the literature and the gap has only been addressed in the context of the United States. This is a research gap which this thesis aims to address. Care transitions, while tackled more often, have only been tackled twice in a sample of all mid- and late life adults, neither in the English context. The period investigated in this thesis corresponds to years when Local Authority social care finances were considerably reduced increasing the need for, and pressures on, unpaid caregivers (Zhang et al., 2021; Zigante et al., 2021). Understanding the relationship between caregiving and sleep disturbance during this period provides evidence relevant to caregiver support priority setting. Further, only two studies used fixed effects models to remove time-constant differences between individuals that may confound associations between care and sleep disturbance (Andres, Golsch, & Schmidt, 2013). This is important to approach a causal understanding of the relationship between caregiving and sleep, by partially addressing selection bias. Several studies also measured sleep via single questions such as the trouble sleeping question from the Euro-D depressive symptoms scale (van de Straat et al., 2021). Using sleep measurements based on more than one aspect of sleep can improve the sensitivity and specificity of indicators of sleep disturbance (Lallukka, Dregan, & Armstrong, 2011). For instance, the single sleep item in the General Health Questionnaire-12 “sleep loss due to worry”, has been found to identify mild rather than more severe sleep disturbance more accurately compared to a multi-question indicator (Lallukka et al., 2011).

3.5.5 Partner health, caregiving, and sleep among couples

The decision to provide unpaid care often hinges on the need for care by a family member due to ill health, disability or frailty (Arber & Ginn, 1990). At the same time, poor health in one partner may disturb the sleep of the other partner, irrespective of

care provision. For instance, where poor health interrupts sleep through medication side effects or symptoms of the disease (Crowley, 2011), or the distress caused by diagnosis of, or living with, an ill spouse (Mills et al., 2009). Therefore, among couples, when one partner is in ill health, sleep disturbance might arise due to disruptions caused by symptoms of the disease itself; distress caused by witnessing a loved one in poor health; or the stress of caregiving (Arber & Venn, 2011). To date, caregiver sleep studies have not included partner health separately, but have sometimes included care recipient health characteristics. Characteristics have been included in one longitudinal study of caregivers based on a clinical population and seven cross-sectional population-based studies, two of which included comparison to non-caregivers. Of these, three studies, all based on data from the United States, found no association with care recipient health. For instance, Secinti and colleagues (2022) compared caregiving to a person with dementia, diabetes, lung disease and cancer to non-caregivers finding all were associated with short sleep duration, but differences between disease type were not significant. Other studies found no association between short sleep and dementia compared to other types of caregiving (Blinka et al., 2022); and disturbed sleep and number of chronic conditions of a care recipient with dementia (Polenick et al., 2018). Among studies finding links, care to a person with dementia has been associated with higher odds of insomnia compared to non-caregivers in Brazil (Laks, Goren, Duenas, Novick, & Kahle-Wroblewski, 2016). Specific characteristics of the person with dementia have been associated with caregiver sleep disturbance. For instance, care recipients having trouble falling asleep after waking up on most nights was associated with sleep interrupted by care and trouble maintaining sleep among caregivers (Osakwe et al., 2022). In addition, a study of predominantly caregivers of people with dementia found more frequent caregiver night-time awakening was associated with care recipients who had fallen in the last month (Leggett, Polenick, Maust, & Kales, 2018). The latter study did not find associations with care recipient ADL or IADL difficulties or chronic conditions, and caregiver sleep may have been disturbed by increased vigilance at night. Finally, longitudinal analysis of four years of data from a clinic-based sample of caregivers of people with Alzheimer's disease found that caregivers had worse sleep quality and greater sleep fragmentation (measured by PSQI and wake after sleep

onset⁸) when their care recipient had more problem behaviours (von Kaenel et al., 2014). A further 23 studies have analysed cross-sectional non-random samples, often of small scale, only three of which included comparison with a group of non-caregivers (Kochar et al., 2007; Mills et al., 2009; Simpson & Carter, 2015). These studies address either patterns of interdependence in the sleep of caregiver and care recipient, drawing on literature investigating interdependence among couples (for reviews of this literature, Carr & Utz, 2020; Meyler, Stimpson, & Peek, 2007); or whether partner health is a significant factor in explaining caregiver poor sleep. Those addressing interdependence in caregiver and care recipient sleep have found associations between sleep measurements of caregiving couples measured concurrently (Bartolomei et al., 2018; Happe, Berger, & FAQT Study Investigators, 2002; Okuda et al., 2019; Peng, Lorenz, & Chang, 2019) and across several months after diagnosis or treatment of the care recipient (Chen et al., 2020; Kotronoulas, Wengstrom, & Kearney, 2016). Results differ within studies by sleep measure, and not all studies have found a relationship (Lee et al., 2014). Nevertheless, these studies indicate that accounting for the effect of being in a potentially bed-sharing couple on sleep may be important when analysing data from couples (Meadows & Arber, 2011). Studies including care recipient health measures in cross-sectional regressions have been carried out among samples of caregivers of people with dementia, Parkinson's disease, and cancer. Increased caregiver sleep problems are associated with care recipients with greater disease severity, behavioural disturbances such as apathy and agitation, anxiety and distress (Gibson & Gander, 2021; Happe et al., 2002; Lee, Yiin, Lu, & Chao, 2015; McCurry, Pike, Vitiello, Logsdon, & Teri, 2008; Mills et al., 2009; Otto et al., 2019; Peng, Chiu, Liang, & Chang, 2018). For instance, among caregivers of individuals with a malignant brain tumour, greater care recipient ADL functional difficulty was associated with shorter caregiver total sleep time and greater wake after sleep onset (Pawl, Lee, Clark, & Sherwood, 2013a). Likely mechanisms linking these partner characteristics to poor caregiver sleep may include the need for night-time care due to toileting or other difficulties, increased vigilance and distress affecting sleep (Gibson & Gander, 2021; Pawl et al., 2013a). Not all studies have found linkages however, and other factors, such as depressive symptoms and caregiver burden, have sometimes emerged as more

⁸ Wake after sleep onset is the amount of time spent awake from initiating sleep to the final awakening (Ohayon et al., 2017)

important (Beaudreau et al., 2008; Chiu, Y. et al., 2014; Kochar et al., 2007; Lee et al., 2014; Lee, Wehrle, Wallen, Ding, & Ross, 2021; Simpson & Carter, 2015). These studies build knowledge of care recipient-caregiver health and sleep patterns among specific clinical groups. Recent population-based studies have expanded evidence but remain geographically limited to the United States and predominantly investigated dementia caregiving, though among much larger and representative samples. Expanding analysis to the full range of caregiving situations and including non-caregivers in population-based longitudinal analysis, would address the differential effects of having a relative in ill health, in addition to any association with caregiving (Amirkhanyan & Wolf, 2003; Han, Kim, & Burr, 2021; Roth et al., 2015). This type of approach has been undertaken in a small section of the caregiver health literature which attempts to distinguish caregiving-related health associations, from the effects of having a relative in need of care, irrespective of care provision (Amirkhanyan & Wolf, 2003), further discussed in Theoretical perspectives, section 4.4. Although this approach has been undertaken most often in the context of parent care (for instance, Amirkhanyan & Wolf, 2006; van den Broek & Grundy, 2018a; Wolf, Raissian, & Grundy, 2015), a handful of studies address spouse caregiving and partner health (Bom et al., 2019; Chiu, C. & Lin, 2019; Luo, 2021; Maguire et al., 2017). Addressing differences according to the gender of the caregiver is also an important area of enquiry (Han et al., 2021), as, for instance, the number of chronic conditions experienced by a partner has been associated with a larger increase in women's depressive symptoms compared to men (Thomeer, 2016). A research gap exists to address the potential effects of partner health and care provision on respondent sleep disturbance among spouses within a nationally representative group of caregivers and non-caregivers.

3.5.6 Caregiving and sleep disturbance during the coronavirus pandemic

As outlined in Background section 2.2.6, the pandemic brought into sharp focus the importance of unpaid care, yet little support was directed specifically to unpaid caregivers during this period (Onwumere et al., 2021). Caregivers reported increased caregiving duties, emotional difficulties and problems accessing health and social care (Beach et al., 2021; Carcavilla et al., 2021). Other potential sources of stress included

isolation, personal health risks, as well as financial and work difficulties (Lightfoot et al., 2021). Consequently, while some caregivers identified positive aspects of the pandemic (Lightfoot et al., 2021), challenging circumstances may have created new, and exacerbated existing, caregiving stressors which could result in sleep disturbance (Beach et al., 2021; Wright et al., 2021). Studies reporting bivariate associations of caregiving and sleep during the pandemic indicated non-resident caregivers reported greater sleep loss than non-caregivers in April 2020 in the UK, particularly sandwich caregivers, caring for children and older relatives (Office for National Statistics, 2020a). Figures vary widely from as few as 9% and 11% of Chinese caregivers reporting perceived reductions in sleep quality (and much higher, 49%, anxiety), in March 2020 (Li, Zhang, Zhang, Li, Ma, An, Chen, Liu, Kuang, Yu, & Wang, 2021a; Li et al., 2021b) to as many as 83% of UK caregivers reporting clinically significant levels of sleep disturbance (PSQI score >5) during May and September 2020 (Onwumere, Kuipers, Wildman, Mason, & Stahl, 2021). Surveys were online and promoted through networks in differing cultural contexts, at times of differing knowledge of, and responses to, COVID-19. The review found eight studies providing multivariable analysis, four of which incorporated comparison to non-caregivers. Among studies not including comparison, factors increasing the likelihood of poor sleep among caregivers included older age (Steel et al., 2022), having had a COVID-19 infection, greater caregiver burden and care duration of fewer than 6 months (Greaney, Kunicki, Drohan, Nash, & Cohen, 2022); while access to positive media messages increased the likelihood of good sleep quality (Li et al., 2021b). Looking after someone with Alzheimer's disease was associated with a reduction in sleep duration from February 2020 to October 2020 in a sample of Chinese caregivers, though analyses were only adjusted for age and gender (Yuan et al., 2022). These studies had no non-caregiving comparison group, were often limited by small sample sizes or samples that, in some cases, differed substantially from population-based descriptions of caregiver characteristics (Greaney et al., 2022). Among studies including non-caregiving controls, two studies found associations between care provision and sleep disturbance and two found no association, including one small study focusing on care for people with dementia in Italy (Busse et al., 2022). A Canadian study assessed family responsibilities (a combined measure of care for young children or being the primary caregiver to someone with a chronic illness or disability) and found an association with greater odds of clinically significant sleep

disturbance (PSQI>5), compared to those without family responsibilities in Canada (Robillard et al., 2021). Different mechanisms for sleep disturbance in the care of young children compared to an adult with chronic illness reduce the insights possible from this study. The other study finding evidence of a relationship drew on a sample of adults from the US, finding caregivers had higher odds of sleep disturbance than non-caregivers, adjusting for a wide range of covariates, though not pre-pandemic health or sleep (Beach et al., 2021). The same study found caregivers who perceived more negative effects of the pandemic on their care provision, for instance, making it harder to access health care for the care recipient, were more likely to report sleep disturbance (Beach et al., 2021). Just over half of the caregivers in the study provided co-resident care, which could include care to an ill child, and 23% of the sample were less than 45 years old (Beach et al., 2021). The only study focusing on mid- and late life caregivers of adults sampled Europeans aged 50 and over, finding non-resident caregivers providing personal care were no more likely to have trouble sleeping than non-caregivers: caregivers had an adjusted probability of trouble sleeping of 10%; 8% among non-caregivers⁹ (Bergmann & Wagner, 2021). This study analysed data from the first wave of SHARE Corona collected in June to August of 2020 and controlled for pre-pandemic health, providing robust evidence that sleep was not affected in the early months of the pandemic among mid- and late life non-resident caregivers (Bergmann & Wagner, 2021). However, caregivers were more likely to have felt sad or depressed, anxious, or nervous, particularly among those providing increased levels of care to a parent (Bergmann & Wagner, 2021). Until May 2022 there has been limited population-based research investigating caregiving and sleep during the pandemic and co-resident care to an adult is a specific gap in the literature.

3.6 RESEARCH GAP AND CONCLUSION

This literature review identified demographic, socioeconomic and health factors linked to the provision of caregiving and to reporting sleep disturbance. These factors are important for understanding the heterogeneity of caregivers and caregiving situations, factors that may increase the likelihood that individuals will provide unpaid care and

⁹ Probabilities were estimated adjusted for covariates held at specific values (values not reported).

may confound associations between caregiving and sleep disturbance. It considered the current evidence of linkages between caregiving and sleep disturbance and identified research gaps. Much of the caregiver sleep literature has focused on caregivers of individuals with conditions such as dementia, Parkinson's disease, and cancer. Studies of clinical groups provide important knowledge for clinicians and other professionals, supporting the development of appropriate interventions. Research addressing the wider population, including the fully range of caregiving situations is more limited. Cross-sectional regression analysis of population-based data can identify associations but are unable to distinguish pre-existing differences between caregivers and non-caregivers, from associations more directly linked to care provision. Longitudinal population-based studies of caregiver sleep have steadily increased in number but remain few and focus mainly on the impact of caregiving transitions into and out of providing care in a small range of contexts, such as the working age population and mainland European countries. Most studies focus on the effects of intensity or frequency of care, while important factors in caregiving such as the location of care and the relationship to the care recipient have yet to be addressed with longitudinal data and advanced methods. Further, gender differences in caregiving and sleep disturbance have been considered in several studies but results are inconsistent. Although several recent cross-sectional population-based studies have addressed care duration and incorporated care recipient condition, no longitudinal study has done so, or addressed how wider partner health may confound associations between care provision and sleep disturbance. These are both substantive and methodological gaps in the literature which could be addressed with longitudinal analysis of population-based data, investigating caregiver sleep separately among women and men and incorporating a wider range of caregiving characteristics, changes over the course of a caregiving episode, and measures of partner health. The next chapter discusses the theoretical frameworks relevant to the topic before outlining specific research aims and research questions that will be addressed in the thesis and hypothesised relationships.

Chapter four - Theoretical perspectives

4.1 INTRODUCTION

The present chapter presents the theoretical perspectives underpinning the research carried out in subsequent chapters and outlines the conceptual framework for the research, the research aims and questions. The research primarily draws on the stress process (Pearlin, Mullan, Semple, & Skaff, 1990; Pearlin, Menaghan, Lieberman, & Mullan, 1981), combined with insights from the sociology of sleep (Meadows, 2005; Williams, 2002). The stress process guides how the characteristics of caregiving, and the caregiver may be associated with sleep disturbance and the ways in which transitions in, stability and duration of care may be important, investigated in chapters seven and eight. Stress process perspectives on health in couples and additional explanatory insights from the sociology of sleep guide analysis of couples in chapter nine. The sociology of sleep is important in providing theoretical insights on the importance of gendered social roles to the patterning of sleep and the ways in which caregiving and partner health may relate to sleep among couples.

A theory sets out “explicit explanations in accounting for empirical findings” (Bengtson, Burgess, & Parrott, 1997, pS72), addressing the processes and reasons that may lay behind research results (Alley, Putney, Rice, & Bengtson, 2010). Developing research questions and hypotheses and interpreting empirical findings is a core part of scientific endeavour, yet without placing interpretations within the context of larger theoretical ideas, findings from disparate research are less likely to build into cumulative knowledge (Alley et al., 2010; Bengtson et al., 1997). The predominant theoretical perspective underpinning this thesis is the stress process (Pearlin et al., 1981) and its application to caregiving through the caregiver stress process framework (Pearlin et al., 1990), most often described as an explanatory model and sometimes a theory (Alley et al., 2010; Humble, Seidel, Yorgason, & Redden, 2020). The use of the stress process as a theoretical device is common across caregiving research (Alley et al., 2010; Humble et al., 2020; Larkin et al., 2018; Roberto, Blieszner, & Allen, 2006). Further, there is a

“strong intellectual tie between current research into stress and classic social theory” (Pearlin, 1999, p386), concerning reactions to every day circumstances and incorporating concepts, for instance, from role theory (Goode, 1960; Merton, 1957; Schieman, 2019; Sieber, 1974), discussed briefly in section 4.2.3. The chapter begins with a brief discussion of the choice of theoretical perspective and the importance of grounding research in wider theory, Section 4.1.1. The stress process is explored in Section 4.2, first by defining stress, stressors and theorised links between stress and sleep, then providing an overview of the stress process and its relevance to caregiving. Section 4.3 introduces the sociology of sleep and theorised relationships emphasising how gendered social roles influence sleep. This is followed by section 4.4 which uses combined insights from the stress process and the sociology of sleep on caregiver sleep and gender, and caregiver sleep in the context of health among couples. The combined conceptual framework for the thesis is then outlined in section 4.5. The research aims and questions are outlined in Section 4.6, and Section 4.7 concludes the Chapter.

4.2 THE STRESS PROCESS

The stress process provides the principle theoretical guidance for the research. This section defines stress and stressors in 4.2.1, and outlines hypothesised links between stress and sleep disturbance in 4.2.2. It describes the interrelated domains in a theorised stress process in general and in relation to caregiving in 4.2.3, paying particular attention to the domains investigated in this thesis: background context and circumstances, primary stressors, and outcomes. Finally, it discusses stress process perspectives on the coronavirus pandemic in 4.2.4.

4.2.1 Defining stress and stressors

Early work on stress considered it to have “its own characteristic form but no particular specific cause” (Selye, 1956, p311) and stressors, predominantly defined as proximal changes in a person’s physical and personal environment, were thought likely to cause harm (1956). This view drew on foundational studies of homeostasis by Walter Cannon in the 1930s and experimental work predominantly using laboratory animal models (Birk, 2021; Pearlin et al., 1981; Thoits, 2010). Since then, sociological and

psychological research has identified the crucial role played by evaluation of events and stressors, appraisal (Lazarus & Folkman, 1984). Life changes are no longer thought always to be harmful (Pearlin & Skaff, 1996). The stress process, described in section 4.2.2, therefore makes a distinction between challenging socioenvironmental circumstances: the stressors; how they are experienced or perceived; and in psychological and physical health manifestations of stress (Aneshensel, 1992; Pearlin, 1989). A modern sociological definition of stress therefore now emphasises “a state of arousal resulting either from the presence of socioenvironmental demands that tax the ordinary adaptive capacity of the individual or from the absence of the means to attain sought after ends” (Aneshensel, 1992, p16). Stressors in the stress process are defined as the “broad array of problematic conditions and experiences that can challenge the adaptive capacities of people” (Pearlin, 2010, p208). Stress responses involve physiological and behavioural changes, to allow an individual to cope with a stressor (Sanford, Suchecki, & Meerlo, 2015). However, when experienced or perceived as stressful or occurring over a prolonged period, they may result in changes in psychological or physical health (Thoits, 2010), including sleep disturbance, discussed next.

4.2.2 Stress and sleep disturbance

The stress process guiding this research is not explicit in theorising the physiological mechanisms which lead to stress. Indeed, this thesis focuses on the social and relational pathways through which sleep disturbance may occur (Pearlin & Bierman, 2013), not including biomarkers of physiological processes. Nevertheless, it is helpful to outline the process through which physiological and psychological stress responses to stressors may lead to longer term changes in health (Epel et al., 2018) and sleep (Juster, McEwen, & Lupien, 2010). These models incorporate an understanding of the normal fluctuations in physiological activity in the body in response to challenge, allostasis (McEwen & Stellar, 1993). Acute stress responses include multisystem physiological activation of immune, neuroendocrine and other systems, and psychological reactivity via processes such as rumination and heightened emotion (Epel et al., 2018). Prolonged or cumulative exposure to stressors can create an imbalance in these bodily mechanisms, allostatic load (Epel et al., 2018; McEwen & Stellar, 1993). With greater

allostatic load, the resting bodily state is consistently higher or lower than previously, and exposure to further stressors is more likely to lead to maladaptive responses (2018; 1993). These processes push physiological activity beyond normal limits and are thought to increase wear and tear on the body, contributing to poor health (2018; 1993). Studies are now investigating potential pathways linking caregiving to measures of allostatic load as well as sleep (Juster et al., 2010).

Sleep disturbance was not explicitly included as a manifestation of stress in the stress process or caregiver stress process framework in their original formulations. However, stress and sleep disruption are thought to be linked to similar systems across multiple levels from the molecular to the behavioural (Kim & Dimsdale, 2007; Lo Martire, Caruso, Palagini, Zoccoli, & Bastianini, 2020) and increases in allostatic load have been linked to sleep disturbance (Juster et al., 2010). For instance, stress responses to physical and psychological stressors act in part through the arousal of the hypothalamo-pituitary-adrenocortical (HPA) system, involving hormones such as cortisol, and modulation of circadian systems, promoting wakefulness instead of sleep (Akerstedt, 2006; Armon, Shirom, Shapira, & Melamed, 2008; Epel et al., 2018; Lo Martire et al., 2020; Lockley, 2018; Venner & Fuller, 2018). Indeed, sleep “appears to function as the opposite of and antagonist of stress” (Akerstedt, 2006, p497). Epel and colleagues (2018) suggest that sleep disturbance along with other somatic responses can be a good measure of the perception of stress in cultures or groups less likely to openly discuss feelings of stress.

4.2.3 The stress process

Stress research encompasses sociological, psychological, and biological perspectives across a variety of disciplines and approaches (Birk, 2021). The stress process approach (Pearlin et al., 1990; Pearlin et al., 1981), often underpins studies of caregiving, though it has a much wider application (Humble et al., 2020). The origins of the approach stem from endeavours to draw together the “extended web of relationships” between social and psychological conditions involved in producing stress into a theoretically defined *stress process* (Pearlin, 1989; Pearlin et al., 1981, p337). The framework incorporated influential work on stress appraisal and coping (Birk, 2021; Lazarus & Folkman, 1984) and has evolved over time, for instance, fostering linkages

with the life course approach developing at a similar time (George, 2014). The formulation of the stress process was tested on panel data relating to unexpected job loss (Pearlin et al., 1981) and bore out theoretical assertions of a dynamic stress process developing “within the contexts and flow of people’s lives” (Pearlin & Bierman, 2013). It was subsequently adapted specifically for caregiving, drawing on research carried out among 550 carers of people with Alzheimer’s disease (Pearlin et al., 1990). The stress process describes how stress may arise due to chronic or acute stressors, influenced by social and economic factors, and sets out how these may be mediated and moderated by personal resources, to influence psychological and physical health expressions of stress (Pearlin, 1989). Five key domains comprise the framework: background characteristics and contexts, primary stressors, secondary stressors, mediating factors and health outcomes (Pearlin, 1989). The five domains are interrelated, and the hypothesised dynamics cannot be captured in single analyses (Pearlin, 1999). The analyses in this thesis focus on background characteristics and contexts, primary stressors, and sleep disturbance as a hypothesised consequence (outcome) of care provision, however each domain is briefly explored to provide theoretical context.

Background characteristics include ascribed statuses such as age, gender, or ethnicity and those that are attained, such as socioeconomic status. These characteristics are embedded within the process, influencing differential exposure to stressors and vulnerability to their effects via personal characteristics, and levels of social and economic resources (Thoits, 2010; Turner, Wheaton, & Lloyd, 1995). This thesis considers the possibility of gender differences in caregiver sleep, stratifying analyses to uncover different associations among women and men, discussed further in section 4.4.1. Wider contexts can include prior circumstances that give meaning to the present, for instance, an individual’s marital relationship history to their perception of their divorce (Pearlin, 1989). For caregiving, context includes the relationship with the care recipient and care duration (Pearlin et al., 1990). Such context has an influence on the extent to which care provision is perceived as stressful (Wheaton, 1990). For instance, the relationship to the care recipient, spouse, parent or another individual, can indicate the extent of choice or obligation felt to provide care, contributing to perceptions of stress (Keating et al., 2019; Pinquart & Soerensen, 2011). Longer duration of care may

correspond to increasing intensity and accumulation of stressors (Gaugler & Teaster, 2006). Care relationship and duration are contexts of care explored in relation to sleep disturbance in chapters seven and eight of this thesis.

Primary stressors are the original circumstance that may cause stress. In Pearlin and colleagues' original work (1981), the primary stressor was unexpected job loss. Stressors have been categorised as life events, chronic strains or major traumas, though these are not exclusive (Turner et al., 1995). Life events often occur at an identifiable time, for instance, the loss of a spouse (Turner et al., 1995) and may be transitions within an existing relationship or situation (George, 1993). Chronic strains creep insidiously into life, and situations of challenging or prolonged care provision are one such strain (Pearlin, 1999). Major traumas may include personal trauma such as an accident (Turner et al., 1995), or social-ecological stressors, experienced by all individuals within a family or community (Milkie, 2010). The coronavirus pandemic is one such major trauma discussed in section 4.2.4. Primary stressors associated with care provision include the number of functional limitations of the care recipient and willingness to provide care (Pearlin et al., 1990). Characteristics of stressors, their strength, whether irreversible or unwelcome are important possible determinants of strain (Pearlin, Schieman, Fazio, & Meersman, 2005). Caregiving hours are investigated as a primary stressor in chapter seven of this thesis. Transitions in caregiving, as well as periods of continued care provide opportunities for studying stability and change in the potential consequences of care provision over the course of a care episode (Skaff, Pearlin, & Mullan, 1996), the subject of chapter eight in this thesis.

An important way in which caregiving can become stressful is through changes it provokes in the wider social and personal environment (Pearlin & Aneshensel, 1994), changes identified heuristically as secondary stressors (Pearlin, 1989; Pearlin, 1999). This domain of the stress process, and the mediating factors domain, are not a focus for the thesis. Briefly, secondary stressors incorporate concepts from role theory (Merton, 1957), social roles referring to statuses in social structure and associated behaviours (George, 1993). Concepts were drawn from role strain (Goode, 1960) and role accumulation theories (Sieber, 1974). Both role strain and benefits from additional

roles are theorised as possible through a stress process, dependent for instance, on context (Schieman, 2019). For instance, role strain (Goode, 1960) may occur with difficulties in balancing time demands of work and care, evidence of which has been found in studies of caregiver sleep (Pearlin, 1989; Sacco et al., 2018; van de Straat et al., 2021). Intrapsychic strains felt within an individual may result from demands on personal capacity, motivation or self-concepts (Skaff & Pearlin, 1992). However, feelings of increased competence, confidence and self-awareness can also arise from caregiving (Pearlin et al., 1990; Pearlin & Aneshensel, 1994) and align to the personal benefits of additional roles foreseen by role accumulation theory (Sieber, 1974). These secondary stressors can emerge across different but overlapping domains of an individual's life, either concurrently or over time, as well as between individuals whose roles intersect, amassing in a process of stress proliferation (Pearlin et al., 2005; Thoits, 2010). Important influences on the stress process at all points are mediating factors such as coping skills and social support, that may reduce the initial and ongoing effects of one or more stressors or may increase their likely impact (Pearlin & Bierman, 2013).

Finally, the outcomes of the stress process are wide-ranging, encompassing expression in "a wide variety of bodily, behavioural or emotional problems" (Thoits, 2010, p48). These general outcomes were by design, as the expression of stress differs between individuals and their unique array of stressors (Pearlin, 1989). Often psychological outcomes such as depressive symptoms, caregiver burden and, less often, physical health outcomes have been studied (Bom et al., 2018; Capistrant, 2016; Pinguart & Soerensen, 2007). Sleep disturbance, the outcome of interest for this thesis, has only more recently been a subject of interest to stress researchers and was not included in original stress process frameworks. Subsequently, it has been added as a health behaviour response to stress (Song et al., 2021; Sørensen, Duberstein, Gill, & Pinguart, 2006) and a secondary stressor or resource (Simpson & Carter, 2013b). In this thesis, characteristics of the caregiver, caregiving situation and among couples, partner health, are viewed as possible stressors and sleep disturbance is hypothesised to be related to caregiving characteristics more likely to be stressful and partner health characteristics. The sociology of sleep adds important explanatory insights to stress process

understandings of the ways in which caregiving and sleep may be differently related among women and men and among couples, addressed in sections 4.3 and 4.4.

In its original formulation, the caregiver stress process framework focused solely on caregivers as the population of interest (Pearlin et al., 1990). It provided theoretical guidance for investigating differing stress responses among caregivers experiencing similar stressors (1990). The stress process was therefore not considered in its entirety, the context relating to differing exposure to the need for care provision was not included. Research taking this approach and inferring poor health from caregiving characteristics has been critiqued for the lack of comparison to suitable non-caregiving controls, research designs leaving open the possibility of selection bias (Brown & Brown, 2014; Roth et al., 2015), see Literature review, section 3.3. In this thesis, the use of panel data and fixed effects models enables the analysis of changes within individuals such that time-constant sources of selection bias are removed, and time-varying factors are adjusted for. This partially addresses selection bias, though unobserved time-varying factors are not addressed by the method, see Methodology section 5.4.3. Further, in chapter nine, differences among individuals by partner health are investigated. These relate to differing need to provide care and the potential stress of experiencing a partner in poor health, discussed further in section 4.4.

4.2.4 The stress process and the COVID-19 pandemic

Chapter nine on caregiving, partner health and sleep, includes a cross-sectional analysis of data collected during the COVID-19 pandemic. While the pandemic touched lives across all social strata, some groups were more vulnerable than others to being infected by the virus, and affected by the societal changes it has brought (Arpino & Pasqualini, 2021; Settersten et al., 2020). Mid- and late life caregivers and care recipients were more likely to be clinically vulnerable to the virus than individuals neither giving nor in receipt of care (Chatzi et al., 2020; Di Gessa & Price, 2021). Societal changes affecting caregivers included lost access to social support and community respite opportunities, and acute perceived financial pressures among those in employment (Bennett, Zhang, & Yeandle, 2020a; Giebel et al., 2021). Sociologists alerted us to possible changes in sleep during the pandemic (Williams, Coveney, & Meadows, 2021). Indeed, differing sleep

patterns have been found, associated with the unequal effects of the pandemic (Falkingham et al., 2022; Jackson & Johnson, 2020; Robillard et al., 2021), including among caregivers in some (Beach et al., 2021), but not all studies (Bergmann & Wagner, 2021). Sociological perspectives on the pandemic encourage a focus on these social differences (Rose et al., 2020; Settersten et al., 2020). Chapter nine uses the first wave of ELSA pandemic data from June-July 2020 to undertake analysis of caregiving, partner health and sleep associations during the pandemic. The stress process provides relevant guidance in this unusual context, as prior research has incorporated stressors affecting whole communities relating to wars and natural disasters (Milkie, 2010). Viewed through the stress process, many changes wrought by the pandemic may be considered primary stressors, giving rise to multiple secondary stressors among vulnerable groups (Chandola, Kumari, Booker, & Benzeval, 2020; Grasso et al., 2021; Heid, Cartwright, Wilson-Genderson, & Pruchno, 2020; Savla et al., 2020). For instance, periods of quarantine have been identified as stressors in previous epidemics and pandemics (Brooks et al., 2020). Proliferating secondary stressors from such movement restriction include those in other domains, such as inadequate essential supplies and financial difficulties; and intrapsychic strains, such as fear of infection and stigma (Brooks et al., 2020). Secondary stressors resultant from physical distancing during the COVID-19 pandemic have been found to vary depending on the prior circumstances of each individual, reflecting the background and context domain in the stress process (Heid et al., 2020). Evidence that entrenched inequalities have been exacerbated through the pandemic (Falkingham et al., 2022) can be partially explained through a stress process where groups such as caregivers and women may have greater exposure to multiple potentially stressful circumstances and access to fewer resources to mitigate their effects (Pearlin et al., 2005; Thoits, 2010). Analysis in chapter nine hypothesises that the pandemic brings new stressors and exacerbates existing stressors for co-resident caregivers, thereby increasing the likelihood of poor sleep (Beach et al., 2021).

4.3 SOCIOLOGICAL PERSPECTIVES ON SLEEP

Sociologists became interested in sleep and sleep patterns as partially socially and culturally constructed only in the latter half of the twentieth century (Aubert & White,

1959; Aubert & White, 1960; Meadows, 2005; Schwartz, B., 1970; Williams, 2002). For this reason, although it has established wide ranging interests, the sociology of sleep is in the early stages of building theoretical frameworks to bridge its ideas and guide further research (Meadows, 2005). Nevertheless, insights from the sociology of sleep are important to add to those from the stress process, providing additional understandings of how and why sleep may be disturbed by the provision of care and by a partner in poor health. It adds sleep-specific insights on possible gender differences in care and sleep, and sleep within couple relationships. This section provides a brief overview of the sociology of sleep before key insights on gender, and caregiving and sleep among couples are discussed in section 4.4.

The sociology of sleep literature firmly acknowledges the fundamental physiological and neurological underpinnings of sleep, while emphasising the many ways in which social norms, roles and relationships influence sleep patterns and practices (Meadows, 2005; Williams, 2002). The area of sociological enquiry into sleep that is of relevance to this research is in the ways in which gendered social roles, particularly but not exclusively in couples, can influence sleep patterns (Walker et al., 2012). It asserts gender differences in sleep due to gendered social roles; and explanations of sleep disturbance in the context of couples, via the interplay between partner health, changing physiology and relationships, including caregiving (Williams, Meadows, & Arber, 2010). As described in Background section 2.5.1, sociological studies of sleep disturbance among caregivers have uncovered mechanisms such as physical night-time care provision; anticipating the need for help by going to bed late or having light sleep, or worrying about the care recipient at night (Arber & Venn, 2011; Bianchera & Arber, 2007; Martin & Bartlett, 2007). A number of explanatory models relating the social environment to patterns of sleep have been proposed, varying in focus, but sharing an emphasis on the importance of social relationships, life course social and physiological changes, and the influence of gender (Grandner, Hale, Moore, & Patel, 2010; Grandner, 2014; Hislop & Arber, 2006; Meadows, 2005; Redline, Redline, & James, 2019). Theoretical developments have integrated a life course approach and role theory into sociological ideas on sleep, providing insights into early life socioeconomic influences (van de Straat et al., 2020), the importance of historical context in shaping roles

influential for sleep (Walker et al., 2012), dyadic sleep and mental health among couples (Chen, 2018) and caregiving transitions and sleep (van de Straat et al., 2021). This latter study found a stress process approach to be relevant (2021). Transitions in caregiving are one of a number of shared interests of the life course and the stress process frameworks which are relevant to this thesis (Aneshensel, 2015; George, 1993; George, 2014; Pearlin & Skaff, 1996; Pearlin et al., 2005; Pearlin, 2010). A life course approach encompasses investigation of “differences in social pathways for negotiating a particular life stage and transitions between life stages” (Alwin, 2012, p216). It attends to heterogeneity associated with differing choices of individuals within the boundaries set by historical time, social and cultural locations and the ways in which individual lives are interdependent across generations, domains of life and within society (Elder, 1987; Elder, 1998; Settersten, 2009). The life course perspective has a wider focus than the stress process, considering transitions as points of change in trajectories of family, work, health (Elder, 1985; Elder, 1998; George, 1993) or care (Fast, Keating, Eales, Kim, & Lee, 2021; Keating et al., 2019). In the stress process, transitions are studied as potential points of stress associated with health outcomes (Pearlin et al., 2005; Skaff et al., 1996). A life course approach could be applied to caregiver sleep and was considered as a possible theoretical framework for the research. However, use of a life course approach would imply differing emphasis in research questions and methodology to the present thesis, for instance, attending to longer periods of time than the transitions studied, or placing greater emphasis on historical time (George, 1993; George, 2014). The stress process supplemented with insights from the sociology of sleep was considered to provide appropriate guidance for formulating the research and interpreting the results of this thesis.

This thesis draws on perspectives from the sociology of sleep, in particular the work of Hislop and Arber (2006) who framed the sleep of mid- and later life women as influenced by four dynamics: physiological factors, institutional factors, relational factors, and biographical transitions differing by age and gender across the life course. Physiological factors include functional impairment and the presence of health problems as sources of sleep disturbance sometimes accompanying older age, via medication or illness symptoms, (Martire et al., 2013; Poole & Jackowska, 2018) and

more general expectations of poorer sleep (Gibson et al., 2014; Walker et al., 2012). Institutional factors relate to patterns of work and sleep, which may be bidirectional (Garefelt et al., 2020); and socioeconomic status, for instance, lower education (Arber et al., 2009) and low levels of wealth associated with poorer sleep (van de Straat & Bracke, 2015). Relational factors include the effect of worries about family members both in and outside the home on sleep (Arber, Hislop, Bote, & Meadows, 2007) and changing relationship quality, for instance, conflict and dissatisfaction in marital relationships related to poorer sleep quality (Chen et al., 2015; Troxel, 2010). Relational factors are also pertinent to the ways in which women and men differ in the enactment of their social roles: for instance, women report their sleep is affected by greater worries about family and care provision, men about household finances (Williams et al., 2010). Finally, biographical transitions, include the changes in sleep during the periods running up to and following caregiving and widowhood (Hislop and Arber, 2006). Insights from this model are combined with a stress process approach to consider caregiving and sleep disturbance in relation to gender, and within couples, in the next section.

4.4 COMBINED INSIGHTS

4.4.1 Gender

Analyses in the thesis are gender-stratified, allowing gender differences to be explored in the relationships between caregiving and sleep disturbance. The stress process and the sociology of sleep provide insights that indicated stronger associations might be expected among women than men, explored in this section. Gender is central to the stress process, women and men likely to be differentially exposed and vulnerable to arrays of stressors, have diverging resources and sometimes different expressions of stress (Pearlin, 1989). Gender-based understandings of care provision and sleep provide insights into how exposure, vulnerability, and expression of stress as sleep disturbance may occur in relation to caregiving. Research indicates that women are more likely to be exposed to caregiving as a potential stressor for much of their life course, and to find the provision of care more stressful (Kim, Mitchell, & Ting, 2019). Women are more likely to undertake care at all but the oldest ages, as detailed in chapter three (Patterson & Margolis, 2019; Robards et al., 2015). Explanations of this

gendered patterns include the influence of social and economic policies, household financial trade-offs between work, family and care, as well as individual, family and societal expectations (Arber & Ginn, 1990; Hooyman, Browne, Ray, & Richardson, 2002; Kim et al., 2019; Stoller, 1993; Weitz & Estes, 2001). For instance, care has historically been considered women's work, with women more likely to undertake these activities (Arber & Ginn, 1990; Stoller, 1993). Older women were more strongly socialised to nurture than men, which some have argued influenced women's orientation towards caregiving roles and more intensive care (Miller, B., 1990). Although men and women provide similar hours of spouse care at higher levels of need in later life (Langner & Furstenberg, 2020), men are more likely to receive informal support or to outsource spouse care than women (Bertogg & Strauss, 2020). These factors accord with greater exposure among women to both care provision and more intense care stressors according to the stress process framework (Pearlin et al., 1990). In addition to gender differences in the prevalence and intensity of care and available resources, differences in the ways in which men and women carry out and experience care may lead to differing perceptions of caregiving as stressful (Carroll & Campbell, 2008; Chappell et al., 2015). Women and men may provide care based on personal notions of masculinity and femininity, and patterns from prior experiences of work and life (Calasanti & King, 2007; Milligan & Morbey, 2016). For instance, women may find care provision more stressful by holding expectations of their own ability to provide care due to previous experiences of child- and other care (Calasanti & King, 2007). They also value maintaining the previous relationship (2007). Instead, men may focus on mastering tasks or managing others paid to perform them; concentrating on maintaining the care recipient's quality of life and allowing them to take a somewhat more emotionally detached stance (Calasanti & King, 2007; Carroll & Campbell, 2008). These differing experiences in providing care relate to gendered roles and intrapsychic strain in the stress process (Pearlin et al., 1990). In relation to sleep, men's sleep may be prioritised within households, particularly when they are in paid work (Meadows, Arber, Venn, & Hislop, 2008). They may have a more individualised view of their sleep and ability to alter their sleep patterns than women (2008). The lives of women, by contrast, are more contingent on others for much of the life course. This extends to night time when they are more likely than men to shape their sleep patterns around the needs of others (Hislop & Arber, 2003b; Hislop & Arber, 2006; Walker et al., 2012). Women have been

found to subsume their own sleep needs more readily than men, first for the needs of children and teens (Arber et al., 2007; Bianchera & Arber, 2007; Burgard, 2011; Hislop & Arber, 2003b; Martin & Bartlett, 2007) and subsequently for partners who snore or are in poorer health (Arber & Venn, 2011; Gibson et al., 2021; Hislop & Arber, 2003b). These perspectives suggest that in addition to women being more likely to provide care and experience sleep disturbance, women may be more likely to experience caregiving as stressful and have more disrupted sleep due to the ways they enact their caregiving or partnership roles.

4.4.2 Couples, caregiving, and sleep disturbance

Although caregiving occurs in relation to at least one other person, caregiver studies framed theoretically by the caregiver stress process often only include individual factors (Amirkhanyan & Wolf, 2003). This mirrors the wider stress process literature; although a smaller subsection has considered the context of stress and illness within couples (Revenson & DeLongis, 2010). Further, while couples sleeping in a shared bed is a common but relatively recent cultural practice (Dittami et al., 2007), sleep among dyads is an area of theoretical interest, but as yet, little explored empirically (Richter, Adam, Geiss, Peter, & Niklewski, 2016; Rosenblatt, 2006; van de Straat, 2020, p135). Sociological perspectives suggest sleep in couples may be “a barometer, sensitive to shifts in the nature of the relationship arising from fluctuations and changes in the health of partners and the impact of life transitions” (Hislop & Arber, 2003a, p203-4). Chapter nine combines stress process and sociology of sleep perspectives to consider how cohabiting couple sleep may be connected through changing health and relationships of co-resident care.

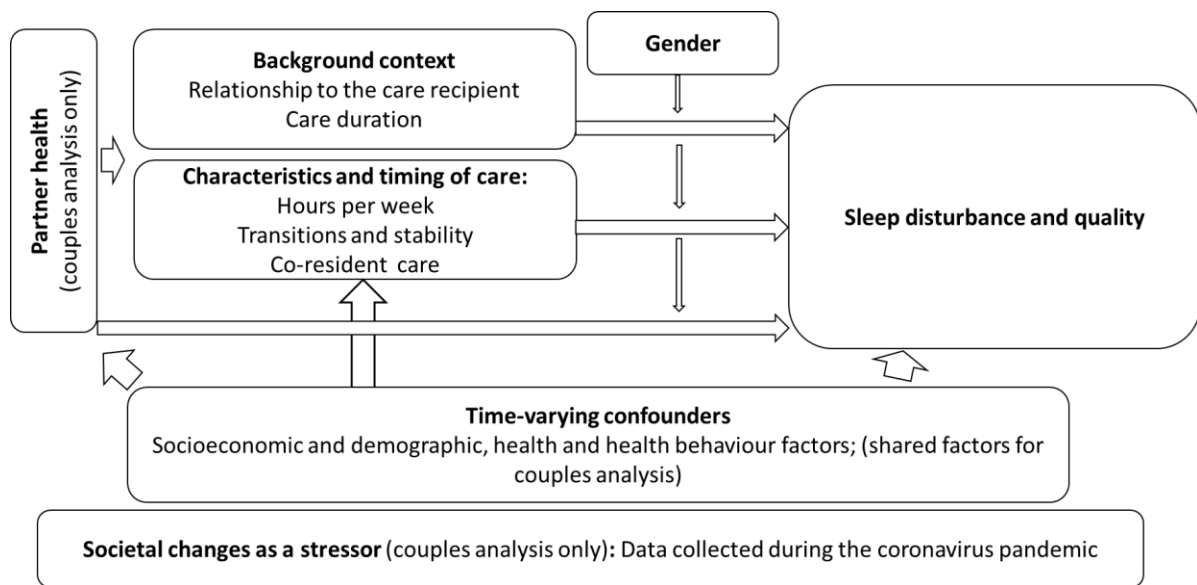
Proliferating stress occurs not only over time but also within the context of close social relationships, including married and cohabiting couples (Pearlin, 2010; Pearlin & Bierman, 2013). For instance, an individual’s stress exposure to a major life event can influence their partner’s health (Moody, Brown, & Ciciurkaite, 2019). In the context of caregiving, a care recipient’s health, such as functional difficulties or number of conditions, is identified as a primary stressor in the stress process framework (Pearlin et al., 1990). However, not all individuals provide unpaid care to a relative with social

care needs (Floridi, Quashie, Glaser, & Brandt, 2021). Among cohabiting or married partners, irrespective of whether a partner provides care, partner ill health may be a source of worry, sadness or stress (Brown et al., 2009; Schulz et al., 2007). A small but important strand of the caregiver health literature aims to isolate the effects of *caring for* a family member in ill health, a caregiving effect, from the effects of *caring about* a family member in ill health, a family effect (Amirkhanyan & Wolf, 2003; Bobinac et al., 2010; Roth et al., 2015). This also allows for the possibility that caregivers gain benefits through feelings of being able to help, which are not accessible to partners who cannot provide care (Amirkhanyan & Wolf, 2003; Schulz et al., 2007). The literature predominantly considers intergenerational relationships of care (for instance, Wolf et al., 2015), while more general studies of health among couples offer insights relevant to situations of marriage and cohabitation (Umberson & Thomeer, 2020). In this literature, the stress process is often drawn upon in a similar way, considering partner health a stressor, caregiving one possible behaviour that might result from partner ill health, and the influence of one partner's health on the other over time (Thomeer, 2016). The sociology of sleep theorises sleep as an often shared experience, and points to the bedroom environment and shared physical and social factors as influences on sleep among couples (Gunn & Eberhardt, 2019; Venn, 2007), including disruptions from restless partners in ill health (Hislop & Arber, 2006). In addition to care provision as a source of sleep disturbance in older age, it indicates having a partner in ill health may disturb sleep, first, by partner sleep disruption due to symptoms of illness or medication, and second, due to distress, worry or sadness (Hislop & Arber, 2003a; Walker et al., 2012). Further, gender differences in sleep may also stem from partner relationships and social roles. These differences are also noted in the literature on partner health; for instance, with health benefits of marriage consistently stronger for men than for women (Umberson & Thomeer, 2020). Chapter nine of the thesis therefore investigates how co-resident care; partner health and sleep are associated among women and men in couples. The chapter hypothesises that sleep may be affected by the provision of care for an ill partner; and the effect of having an ill partner, irrespective of care provision, due to distress, or partner sleep disturbances.

4.5 CONCEPTUAL FRAMEWORK FOR THE RESEARCH

The conceptual framework for this thesis is outlined in Figure 4.1 and combines stress process and sociological perspectives on sleep in the study of caregiving and sleep in mid- and later life adults as a whole and among cohabiting couples. The stress process suggests that contextual factors of care provision such as the relationship to the care recipient and duration of care may be implicated in the extent to which care is experienced as stressful, leading to sleep disturbance. Hours of care per week are included as a primary stressor, and transitions and stability within a care episode are also explored in relation to sleep disturbance. Among cohabiting couples, partner health is included as a determinant of co-resident care provision, as well as a primary stressor with a hypothesised direct pathway to a respondent's sleep. This second pathway corresponds to the stress of *caring about* a partner in ill health and the influence of partner health on sleep through night-time disruption due to medication or symptoms. The framework expects that women and men may be differently exposed to caregiving stressors and risk factors for sleep disturbance, and experience and perceive care provision and sleep in different ways due to differing gendered social roles. Socioeconomic, demographic, health, and health behaviour factors relevant to caregiving and sleep and shared factors in analysis of couples are incorporated into analyses and were drawn from the theoretical frameworks, caregiving literature and epidemiological studies of sleep disturbance. Finally, the effect of the COVID-19 pandemic is captured as a major societal level stressor. The aim of the research, individual research questions and an introduction to the methods adopted are discussed next with separate conceptual models for each research question, Figures 4.2 to 4.5, providing further detail on categories of interest and covariates.

Figure 4.1 Conceptual framework



4.6 RESEARCH AIMS AND RESEARCH QUESTIONS

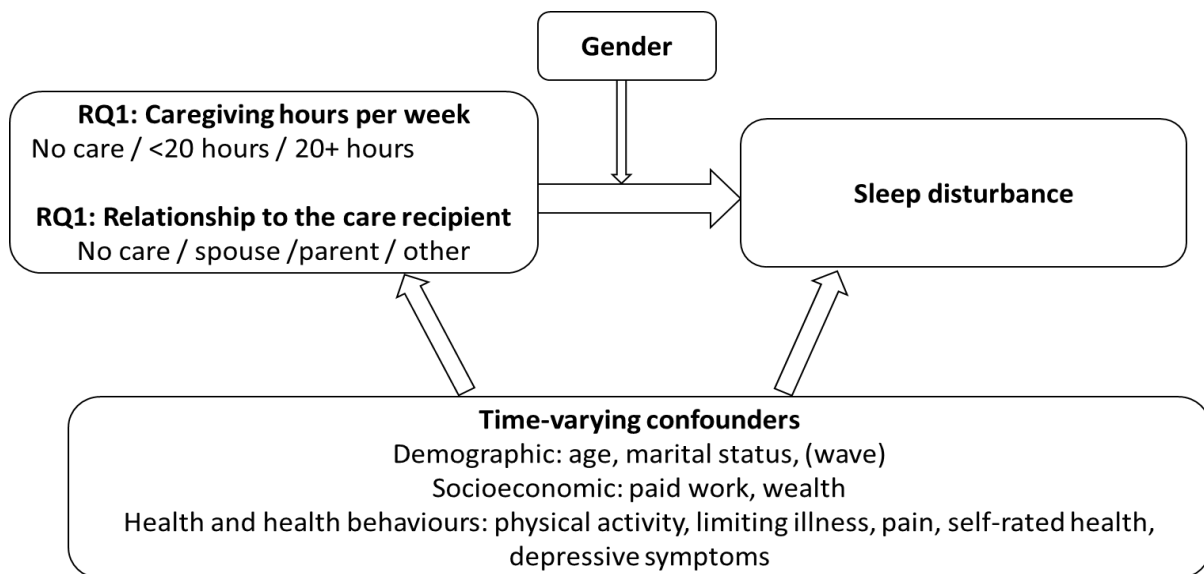
The thesis aims to examine the longitudinal linkages between unpaid caregiving and sleep disturbance among women and men in mid- and later life. It aims to understand the characteristics of caregiving that are associated with sleep disturbance, the importance of transitions, stability, and duration of care, and how caregiving and partner health are related to sleep disturbance in the context of cohabiting couples. Longitudinal data and panel models, predominantly fixed effects models, allow a focus on individual changes over time, removing time-constant sources of bias (Andres et al., 2013). This enables interpretations that move closer to causal understandings of the links between unpaid care and sleep disturbance. Analyses are gender stratified to adjust for gender differences in the exposure to care provision and a sex-standardised measure of sleep disturbance adjusts for the higher likelihood in general among women of reporting disturbed sleep compared to men. Gender differences in sleep disturbance can therefore be identified, which may indicate differences in the perceived stress when providing the same care or differences in how caregiver stress is expressed among women and men.

Research questions

1. How are caregiving hours per week (less than 20 hours per week and 20 or more hours per week) and caregiving relationship (spouse care, parent/in-law care or care for others) longitudinally associated with disturbed sleep among women and men?

Investigation of this research question uses waves 4, 6 and 8 of English Longitudinal Study of Ageing, ELSA data and fixed effects models to regress sleep disturbance on caregiving hours and then relationship to the care recipient, adjusting for demographic, socioeconomic, health and health behaviour confounding factors, Figure 4.2. Greater intensity of care is theorised as more stressful in the caregiver stress process framework through its impact on time available to undertake other roles, potential for conflict within important family relationships and feelings of being overwhelmed in the caregiving role (Pearlin et al., 1990). A threshold of 20 or more hours of care per week has been associated with poorer mental health and problematic sleep, see Methodology section 5.3. It is assumed that the same amount of care may also disrupt sleep in mid- to later life, as a possible consequence of caregiving stress (or among a smaller number of individuals, as a result of caregiving at night, though this is not able to be measured). Providing care for different individuals is likely to be influenced by varying levels of choice, constraint, obligation and motivation (Keating et al., 2019); as well as combinations of secondary stressors and resources such as social support (Bertogg & Strauss, 2020). Spouses are considered most likely to incur sleep disturbance as the circumstances of spouse care are likely to bring greater burden with fewer opportunities for relief (Chappell et al., 2015). Spouses are more likely to undertake personal care and undertake care at night. Parent caregivers may be more able to benefit from social opportunities and respite offered by work and other family roles (Barnett, 2015). Care for individuals other than a spouse or parent is more likely to be undertaken by choice and involve less intense care activities (Keating et al., 2019) and expected not to incur sleep disturbance. Caregiving was expected to be associated more strongly with sleep disturbance among women than men in all research questions, due to differences in perceived stress of caregiving (Calasanti & Bowen, 2006) and the way in which caregiving and partner roles are enacted that may disadvantage women's sleep more than men (Meadows et al., 2008).

Figure 4.2 Conceptual model for research question 1



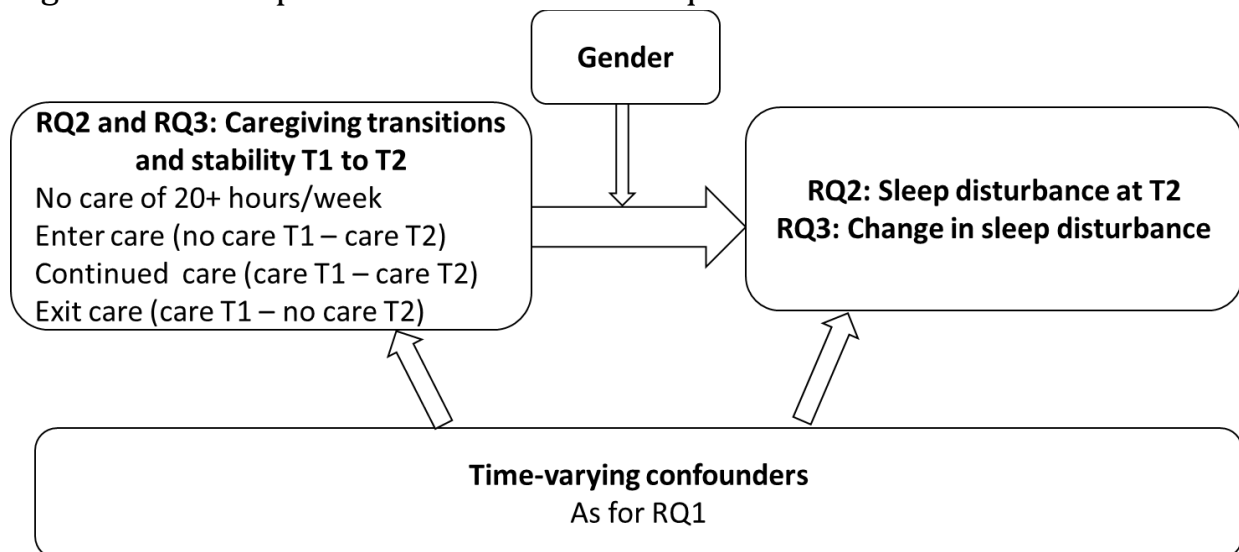
Abbreviation: RQ, research question

2. What are the longitudinal relationships between caregiving transitions (starting and ceasing caregiving of 20 hours or more per week) and periods of stability (continued caregiving) and sleep disturbance among women and men?
3. How do these relationships change when change in sleep disturbance is measured?

In research questions 2 and 3 care transitions and stability were measured between consecutive waves: wave 3 to 4, wave 5 to 6 and waves 7 to 8. Research question 2 used random and fixed effects models in a similar way to research question 1. Research question 3, used pooled multinomial logistic regression to model change in sleep disturbance, Figure 4.3. These research questions relate to stability and change in a caregiving episode. Within the context of stress process research, unpaid care has been theorised as a career, changing through time (Pearlin & Aneshensel, 1994). Stress process scholars consider transitions in social roles as points of potential stress (Skaff et al., 1996), including becoming a caregiver, or exiting that role due to recovery, institutionalisation or death (Gaugler & Teaster, 2006; Pearlin, 2010). In these research questions, care transitions were analysed for care of 20 or more hours per week, which was hypothesised as likely to be a stressor in research question 1 above. Recent studies of caregiver sleep transitions have found disparate results by gender and transition

point. The analysis attempts to reduce heterogeneity among individuals identified as caregivers by focusing on transitions in care thought to be more likely to be stressful. Starting to provide care of 20 hours per week is likely to require changes to be made in other areas of life to accommodate care provision and adjustment to new role demands (for instance, Moral-Fernández, Frías-Osuna, Moreno-Cámara, Palomino-Moral, & Del-Pino-Casado, 2018). Continued care over several waves, represents a significant commitment of time and energy, potentially involving changes to social life, work or other opportunities (Pearlin et al., 1990). Such care may be an example of the “problematic continuities in people’s lives” that cause stress (Pearlin, 1989, p244). Finally, ceasing care, whether through bereavement or transferring the care recipient to a nursing home may include loss of a cherished relationship, legacy sleep habits from the final stages of care, and a period of reestablishment of old sleep habits (Hislop & Arber, 2006; Walker et al., 2012). Sleep disturbance was expected at each stage of a caregiving episode, and to increase over time, reducing on ceasing care in line with other research (Sacco et al., 2018; van de Straat et al., 2021). As for research question 1, associations were expected to be stronger among women than men, assuming women to find these the transition to caregiving, continuing to care over a longer period more stressful than men.

Figure 4.3 Conceptual model for research questions 2 and 3

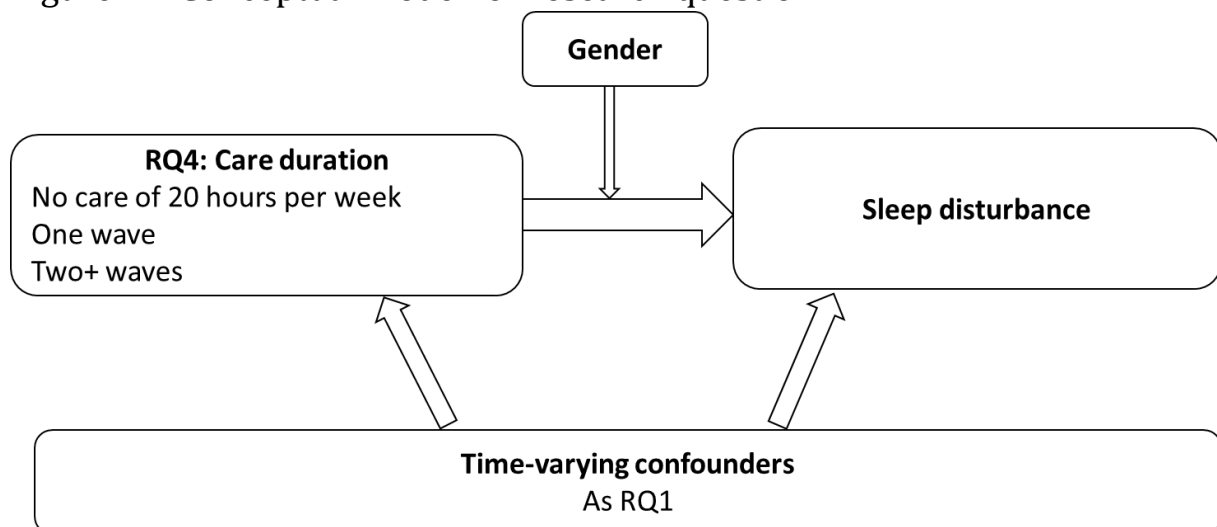


Notes: caregiving transitions coded between consecutive waves. Sleep disturbance changes coded between waves 4, 6 and 8. Abbreviations: RQ, research question; T1, time 1; T2, time 2.

4. How is duration of caregiving (over one wave, or two or more waves) associated with sleep disturbance?

Random effects models were used to assess associations between care duration (no care, one wave, or two or more waves of care of 20 or more hours per week) and sleep disturbance, as coefficients for variables that do not change over time cannot be estimated by fixed effects models, Figure 4.4. Duration of care was included in the caregiver stress process framework in the background and context domain and can provide an indication of the type, persistence, and number of likely stressors (Pearlin et al., 1990). For instance, prolonged care for individuals with mental health difficulties or chronic illness may increase in difficulty and erode social contacts and support over the passage of time (Fast et al., 2021; Keating et al., 2019). The caregiver stress process posits ebbs and flows in a care situation; but anticipates stressors are likely to accumulate over time in intense care situations (Aneshensel, 2015). Although caregivers may also adapt to the demands of the care experience, for instance by altering coping patterns over time (Zarit et al., 1986), mixed results have been found in empirical studies (for instance, Lacey et al., 2018; Yuan & Grünh, 2020). In this thesis, longer care duration was expected to be associated with sleep disturbance, given evidence similar findings for distress among caregiving women in the UK (Lacey et al., 2018).

Figure 4.4 Conceptual model for research question 4



Abbreviation: RQ, research question

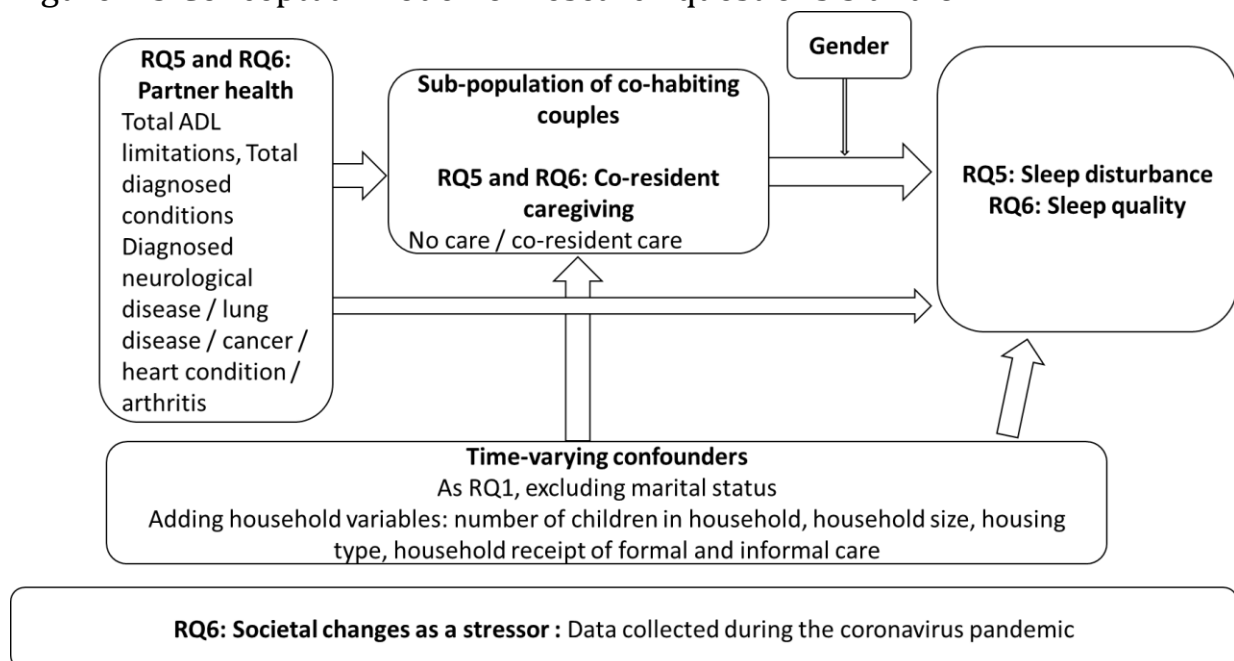
5. Among cohabiting women and men, how are co-resident care and partner health associated with sleep disturbance?
6. How are co-resident care and partner health associated with sleep quality during the COVID-19 pandemic?

Research questions five and six incorporated partner health into a study of co-resident care in cohabiting couples, Figure 4.5. General partner health measures were included along with partner diagnosed health conditions previously associated with sleep disturbance (for instance, Poole & Jackowska, 2018). Question five was investigated using a two-stage approach. First, a multilevel model was used to analyse cross-sectional associations between caregiving, partner health and sleep disturbance among couples. This analysis indicated how much variance remained that was explained by being in a couple, from shared factors not already adjusted for (Snijders & Bosker, 2012). Second, longitudinal fixed effects models analysed co-resident care, partner health and sleep disturbance among individuals over time. Research question six was investigated with a cross-sectional analysis of wave 1 of the ELSA COVID-19 sub-study, collected during June-July 2020, to explore the relationships between co-resident care, partner health and sleep quality in the stressful circumstances of the pandemic. It used the same conceptual model as research question five, but analysed sleep quality rather than disturbance based on the questions available (NatGen Social Research, 2020c).

A partner in poor health is a risk factor for providing co-resident care among cohabiting adults (Floridi et al., 2021). At the same time, having a partner with more health conditions, limitations to activities of daily living or conditions which are associated with poorer sleep may affect a respondent's sleep (Hislop & Arber, 2006). Partner health changes therefore may partially or fully confound any association between co-resident caregiving and sleep disturbance. Three possible reasons are considered for partner health being associated with respondent sleep disturbance. First, a partner's poor health may induce concern and stress. Second, a partner's health may provoke the respondent to provide co-resident care, sleep disturbance resulting from providing that care. Third, sharing a bed with a partner in poor health may lead to sleep disturbance through physical disturbance where the partner experiences pain, side effects of medication or symptoms of the condition (Hislop & Arber, 2006;

Thomeer, 2016). Therefore, partner health factors were expected to be associated with respondent sleep disturbance and their addition to the model was expected to reduce any association between co-resident caregiving and sleep disturbance. In question six, the COVID-19 pandemic provoked widespread changes in the social and economic fabric of society, which can be categorised as stressors (Bergmann & Wagner, 2021; Heid et al., 2020). The circumstances of the pandemic were expected to create new stressors and exacerbate existing stressors among co-resident caregivers, leading to a stronger association with sleep quality (for instance, Beach et al., 2021). In the context of couples, women were expected to have more disrupted sleep associated with care provision than men. For instance, men may more often than women view caregiving as a set of skills to learn and tasks to undertake, allowing more emotional distance, though not an uncaring attitude. They may also receive more recognition for their caregiving than women (Calasanti & King, 2007). Further, women may have developed sleep patterns attuned to the needs of others during their earlier lives. Their sleep may be more likely to be disrupted by worries, their partner's restlessness or distress, and active care of their spouse than men (Hislop & Arber, 2006).

Figure 4.5 Conceptual model for research questions 5 and 6



Abbreviations: ADL, activities of daily living; RQ, research question

4.7 CONCLUSION

This chapter presented the theoretical underpinnings for this research: the stress process and its application to the specific situation of unpaid care, along with insights from the sociology of sleep. It drew out insights relevant to caregiver sleep from these chosen perspectives and described the conceptual framework for the thesis and the research aim and questions. The stress process indicated characteristics of caregiving and the caregiver which may be more likely to be stressful and lead to sleep disturbance. Further it suggests longer care duration and key transitions in care provision that may be linked to sleep disturbance. The sociology of sleep provided insights into the gendered social relationships that influence sleep, the reasons why women may experience sleep disturbance more than men, and why partner health may be an important factor in the interplay of gender, health, and caregiving among couples. Chapter five provides a detailed description of the methodology employed to investigate the research questions, including data, variables, and statistical approach.

Chapter five - Methodology

5.1 INTRODUCTION

The present chapter provides details of the methodology used, describing the data, the variables and statistical methods employed. Section 5.2 discusses the rationale for using data from the English Longitudinal Study of Ageing, ELSA (Banks et al., 2019), and briefly describes the study. Variables used in analyses in chapters 6 to 9, and their measurement, are described in section 5.3, starting with the key dependent and independent variables and then covariates. The statistical methods employed are discussed in section 5.4. The section outlines the descriptive analyses undertaken before introducing panel models and fixed effects models specifically. Alternative approaches are briefly described and the rationale for choosing fixed effects are explained. Other inferential models used in the analyses, and model specifics: gender stratification, model covariates and the thesis approach to missing data are also outlined. Section 5.5 concludes the chapter.

5.2 DATA

This section briefly describes the data source used in this thesis, the English Longitudinal Study of Ageing, ELSA, including study respondents, response rates and weighting variables. It provides a brief rationale for the use of this data and then details the ELSA waves, respondents and weights used in the analyses carried out in this thesis.

5.2.1 English Longitudinal Study of Ageing

ELSA collects a wide range of social, economic and health data from a representative sample of adults aged 50 and over, along with their partners, living in private households in England (Stephens, Breeze, Banks, & Nazroo, 2013). Personal interviews are conducted with each respondent every two years (a wave), as well as self-completion questionnaires at each wave and biodata collection every four years. The first wave of ELSA interviews was carried out in 2002 with a sample of 12,099 women and men, and by February 2022, nine main waves of data have been collected (NatCen Social Research, 2020a). Two additional waves of data were collected during 2020,

providing information on individuals' physical and mental health, finances, social activity and access to health and social care services during the unique circumstances of the pandemic (NatCen Social Research 2020). Ethical approval for the ELSA study was granted by the National Research Ethics Service, and was approved by the relevant Research Ethics Committee at each wave (Breedon, Hussey, Deepchand, & Norton, 2018; Bridges, Hussey, & Blake, 2015; Cheshire et al., 2012; NatCen Social Research, 2020c). In this thesis, the standard anonymised datasets were used, available to the public once registered with the UK Data Service, so no further approvals were required.

The original ELSA sample was initially drawn from individuals responding to the Health Survey for England (HSE) in 1998, 1999 and 2001 who had consented to being re-contacted, forming the original study cohort. HSE is a nationally representative annual survey, the sample for which is drawn from the Postcode Address File (Breedon et al., 2018). Subsequent ELSA refreshment samples (cohorts) have been drawn from further HSE years to ensure representation of the youngest age range in ELSA as the original sample grows older (in waves 3, 4, 6 and 7); and to compensate for sample attrition at older ages (wave 4) (Breedon et al., 2018). Core members of ELSA are classified as individuals who took part in HSE, were age-eligible according to eligibility criteria for each cohort and were interviewed at their baseline wave. Supplementary data collected via interview is available for younger and older partners, partners who did not live with a core member at the time of their original interview or did not participate in HSE¹⁰. In this thesis, samples were drawn from core members only. Partner health data was included in analyses in chapter nine, including from interviews with nominated proxies for individuals who were unable to respond because of cognitive impairment, physical or mental ill health, or being away in hospital or temporary care (NatCen Social Research, 2018), see chapter nine section 9.2 for further details. At each ELSA wave, core survey questions are included, supplemented by topics included on a less frequent basis. A module on respondent sleep was included in ELSA waves 4, 6 and 8 (Breedon et al., 2018) and these waves form the primary sample for the thesis, see Table 5.1.

¹⁰ Partners were included as core ELSA members in the COVID-19 sub-study to maximise sample size. However, partners were only weighted in the cross-sectional and not longitudinal weight, the weight used in the analysis conducted in this thesis (NatCen Social Research, 2020c).

The ELSA project conducts robust fieldwork procedures to ensure high response rates and preserve the representative nature of the dataset. Individual response rates are calculated as the percentage responding of the total eligible (or not confirmed as ineligible) individuals in each cohort. These range from 67-70% in HSE waves used for the original cohort, 63-78% at wave 4, 55-85% at wave 6, 74-84% at wave 8 and 75% at COVID-19 sub-study wave 1; ELSA wave and technical reports provide further detail (Breedon et al., 2018; Bridges et al., 2015; Cheshire et al., 2012; NatCen Social Research, 2020c). A total of 11,050 interviews (9,886 of which were core members) were carried out at Wave 4; 10,601 (9,169 core members) at Wave 6; 8,445 (7,223 core members) at Wave 8 and 7,040 (5,825 core members) at COVID-19 wave 1 (NatCen Social Research, 2018; NatCen Social Research, 2020c). To adjust for ELSA's complex sample design and clustering within households, cross-sectional and longitudinal weights and household identifiers are provided with each wave. Cross-sectional weights are calculated using patterns of non-response, population estimates of age and sex at the relevant year and demographic and socioeconomic characteristics associated with non-response, by cohort, see individual technical reports for details (Breedon et al., 2018; Bridges et al., 2015; Cheshire et al., 2012). Section 5.4.4 below provides further detail on the weights used in analyses.

5.2.2 Alternative datasets

Other datasets were considered less suitable for the research than ELSA in their availability of sleep or caregiving variables, or potential longitudinal sample size. Datasets with only a single sleep question (the Survey for Health, Ageing and Retirement in Europe), sleep questions which could not be combined to make a standardised measure (The Irish Longitudinal Study on Ageing) or having fewer than three waves of sleep data (The Northern Ireland Cohort for the Longitudinal Study of Ageing) were discounted as possible data sources. Also discounted was the Health and Retirement Survey, HRS. HRS includes sleep questions aligning to those in the Jenkins sleep scale, JSS (Jenkins et al., 1988), in its health status module from 2004 onwards, and care provision is measured via a series of questions in the Functional difficulties and Helpers module (Health and Retirement Study, 2020; Jain, Min, & Lee, 2016). HRS

was discounted however, as the social care environment in the United States differs markedly from England, the context of interest. For further discussion of this choice, see chapter ten section 10.3, limitations and section 10.5, possibilities for future research. The UK Household Longitudinal Survey (Knies, 2015), included three waves of sleep data and suitable care questions. ELSA was favoured however, as the UK Household Longitudinal Survey sleep module did not include a question on waking up tired, precluding use of a validated sleep disturbance measure such as the JSS (Jenkins et al., 1988) or Pittsburgh Sleep Quality Index, PSQI (Buysse et al., 1989). Sleep variables also had high levels of missingness in wave 1 due to their inclusion in the self-completion questionnaire (Knies, 2015). For these reasons, ELSA was chosen as the dataset with a sufficient longitudinal sample size, a wide range of caregiving and health measures, and questions that could be combined into a measure based on the validated sleep measure, the JSS (Jenkins et al., 1988).

5.2.3 ELSA waves used in the thesis

In this thesis, data was drawn primarily from waves 4, 6 and 8, which included a sleep module in the main interview, see Table 5.1. Chapter six provides descriptive statistics for the eligible sample of individuals from each of waves 4, 6 and 8 and includes details of how each subsequent sample for chapters seven, eight and nine were selected. In addition to waves 4, 6 and 8, in chapter eight, caregiving data from waves 3, 5 and 7 was used to calculate caregiving transitions from the previous wave (waves 3 to 4, waves 5 to 6 and waves 7 to 8). In chapter nine, analysis of the first wave of the ELSA COVID-19 sub-study was carried out. COVID-19 models also included several variables drawn from wave 9 which were unavailable in the sub-study data. Finally, due to an error in feed-forward information, partner health responses for diagnosed conditions for each wave were re-coded from available responses for all ELSA waves, as guided by the ELSA team, see section 5.3 and Appendix B for further details.

Table 5.1 Variables and waves of ELSA data used in analyses

	Waves 1 and 2 2002/3 and 2004/5	Wave 3 2006/7	Wave 4 2008/9	Wave 5 2010/11	Wave 6 2012/13	Wave 7 2014/15	Wave 8 2016/17	Wave 9 2018/19	COVID-19 wave 1 2020
All chapters									
Sleep module			X		X		X		
Demographic, socioeconomic and health questions			X		X		X		
Chapter seven									
Caregiving hours and relationship			X		X		X		
Chapter eight									
Caregiving transitions		X	X	X	X	X	X		
Chapter nine									
Co-resident care (main analysis)			X		X		X		
Partner health, diagnosed conditions (main and COVID-19 analysis) †	X	X	X	X	X	X	X	X	X
Sleep quality question (COVID-19 analysis)									X
Caregiving questions (COVID-19 analysis)									X
Covariates (COVID-19 analysis)								X	X

† Partner diagnosed conditions were recoded for each wave from all previous responses to ELSA from wave 1 onwards, as advised by the ELSA team, due to an issue with the feed-forward mechanism from previous waves, see Appendix B.

5.3 VARIABLES AND THEIR MEASUREMENT

In this section, details are provided of the variables used in the analyses and their measurement. The section starts with the dependent and independent variables, sleep disturbance and change in sleep disturbance, caregiving hours, caregiving relationship, caregiving transitions and caregiving duration, followed by covariates. Variables used in the analysis of COVID-19 sub-study data are included in relevant sections. Several variables were initially included in analyses but were not adjusted for in the final analyses as no substantive difference was discerned in the model results and they were not key variables within the literature or theory. These were indicators of volunteering and grandparenting roles of individuals, smoking and alcohol use. Initial analyses incorporating measures of perceived stress (the demand and control scale) and inflammation (C-reactive protein) were also not taken forward due to longitudinal sample size constraints as variables were included in the self-completion questionnaire and nurse visit respectively. For instance, nurse visits were offered to ELSA core members who had completed a full interview; however, in wave 8 a visit was only offered to a subsample of respondents who had consistently received a nurse visit, 3,714 or 94% of whom took up the offer (NatCen Social Research, 2020a).

5.3.1 Dependent and independent variables

Sleep disturbance: The primary dependent variable in this thesis is sleep disturbance. ELSA includes a sleep module in waves 4, 6 and 8, each four years apart. The questions in the ELSA sleep module mostly follow the Jenkins sleep scale (Jenkins et al., 1988) and the Pittsburgh Sleep Quality Index (Buysse et al., 1989). There are five core questions in the module on sleep quality, sleep duration, time taken to fall asleep, remaining asleep and tiredness on waking, increasing to seven questions including trouble staying asleep and dozing and napping in waves 6 and 8. Although there is no accepted standard sleep disturbance measure, this thesis used a measure of sleep disturbance combining three variables from the Jenkins sleep scale. This is in line with previous research using the three-variable version of the scale (rather than the alternative four variable version of the scale which could only be calculated from wave 6 data onwards) (Jenkins et al., 1988). Respondents were asked “*How often do you ...*” “*...have difficulty falling asleep?*”, “*...wake up several times per night?*”, “*...wake up after your usual amount of sleep feeling*

tired?". Answer categories ranged from "not during the last month", coded 1, to "three or more times per week", coded 4 and were summed and averaged. As no clinically significant cut-off point has been derived for the Jenkins scale, studies have used differing cut off points and levels of measurement, including summary scores by tertials (Miller, M. A., Wright, Ji, & Cappuccio, 2014); sex-specific tertiles (Jackowska et al., 2013); and a binary variable coding sleep disturbance as the highest sex-specific quartile (Di Gessa et al., 2017). The score has also been used as a continuous independent variable (Jackowska & Steptoe, 2015; Jackowska & Poole, 2017; Poole & Jackowska, 2018). In this thesis, a dichotomous variable was created, coding sleep disturbance for scores in the highest sex-specific tertile (coded 1) compared to low or no sleep disturbance (the reference category coded 0). The Stata *xtile* command requires tied scores to be coded to the lower tertile (StataCorp, 2017a) and resulted in counter-intuitive distribution of the dichotomous variable. While women reported more frequent sleep difficulties than men in going to sleep, staying asleep and waking up tired, a smaller percentage of women were coded as reporting disturbed sleep (22% in wave 4) than men (30% in wave 4), see Table 6.1 in section 6.3. Highest sex-specific sleep tertile was coded for men who had an average score of between 2.66 and 4, and for women between 3.33 and 4. To test sensitivity to measurement level, continuous sleep disturbance scores were used in sensitivity analyses, with range 1 to 4 and relatively normal distribution (skewness 0.31, kurtosis 2.18, wave 4).

Change in sleep disturbance: Changes in sleep disturbance were investigated in chapter eight. The main dataset was reshaped to wide format and changes in sleep disturbance responses were coded between waves 4 and 6, waves 6 and 8 and, for those individuals missing wave 6, waves 4 and 8. Using the dichotomous sleep disturbance variable, individuals reporting no sleep disturbance in both waves were coded as the reference category, stable low sleep disturbance. Further categories were coded 1, improved sleep (sleep disturbance in the first wave, no disturbance in the second wave); 2, sleep disturbance onset (no disturbance first wave, sleep disturbance second wave) and 3, stable sleep disturbance (sleep disturbance in both waves) (van de Straat et al., 2021). Sensitivity analyses were carried out having coded as missing individuals who had the larger gap of change between waves 4 and 8 but results did not differ and

are not presented. Change in sleep disturbance was modelled as a change score for sensitivity analyses of the continuous variable, see chapter eight, section 8.4 and Appendix table E4.

Sleep quality: In chapter nine, analysis was carried out of ELSA COVID19 sub-study data. The full set of sleep questions were not included in the shorter online pandemic survey, but a question on sleep quality was available. Respondents were asked *“In the past month would you say the quality of your sleep was...?”*. Responses of *Good, Very Good or Excellent* were coded 0, “Good or better sleep quality” (reference category) and responses of *Fair or Bad*, coded 1, “Poor sleep quality”.

Caregiving: The caregiving independent variables used in the thesis are detailed below and include caregiving hours and relationship to the care receiver, used in chapter seven; caregiving transitions/stability and care duration, considered in chapter eight, and caregiving location assessed in chapter nine. Each caregiving variable was derived from a variable identifying adult caregivers, described in this section. To identify caregivers, ELSA respondents are asked *“Did you do any of these activities in the last month?”* with an answer category *“Cared for someone”*, in the Work and Pensions module. In wave 4, answering yes to this question was a prerequisite for subsequent questions on caring in the Effort and Reward module, which identified caregivers with the question *“Did you look after anyone in the last week? (by “look after” we mean the active provision of care)”*. In wave 6, the routing for the question was changed and all individuals were asked both questions. To maintain consistency across waves, caregiving was coded only for individuals who answered yes to caring in the last month and looking after someone in the last week. All other individuals were coded as non-caregivers, following other studies (Rutherford & Bu, 2018; Yuan & Grünh, 2020). This thesis focused on care provision to adults, therefore individuals who exclusively looked after children or grandchildren and no adults were coded as not caregiving but remained in the sample. Individuals who looked after both an adult and a child or grandchild were coded as missing, as hours of care could not be disaggregated for older and younger care recipients. This included 60 individuals in wave 4 (0.5% of all

interviewed individuals), 133 individuals in wave 6 (1.2% of individuals) and 75 individuals in wave 8 (0.9% of individuals). The survey question used to make these distinctions is described below (caregiving relationship).

Hours of care: Caregiving hours were analysed in chapter seven. Respondents were asked “*How many hours in the past week did you do this [look after anyone]?*”, answers given in whole hours from 0 to 168 hours. Responses were recoded into individuals providing no care (reference category), caregiving for less than 20 hours per week (coded 1), and caregiving for 20 hours or more (coded 2). This is an often-used caregiving intensity distinction, caregiving for 20 hours or more having been associated with poorer health (Bom & Stöckel, 2021; Hirst, 2005) and trade-offs between paid work and care provision (Carmichael & Ercolani, 2016). Recent studies have identified health effects of caregiving for as little as ten hours per week when combined with paid work (Carr et al., 2016) and associated with quality of life (Sacco et al., 2022). ONS Census 2021 caregiving categories were expanded to capture 10-19 hours per week (Office for National Statistics, 2021). However, other research has indicated such lower hours of care can be associated with physical health benefits when combined with paid work, and no effects on mental health (Bom & Stöckel, 2021). The cut-off point of 20 hours is therefore more relevant to the sample in this research of both paid workers and those not in paid work.

Relationship to the care receiver: chapter seven also included analyses of care relationship. ELSA captures relationship to the care recipient by asking “*What relation is this person to you?*”. A caregiving relationship variable was coded distinguishing no care (the reference category), from spouse or partner care (coded 1); care for a parent or parent-in-law (coded 2); and other care relationship (coded 3). Parent and parent-in-law caregivers were included together as individuals in these roles have been found to have similar characteristics (Pinquart & Soerensen, 2011). Other care included caregiving for a friend, neighbour, or an adult relative other than a spouse or parent/in-law. Caregiving for more than one person was coded to one category in line with theoretical expectations of the importance of spouse compared to other types of care. Spouse care was prioritised over parent and other care, and parent care prioritised over

other care. As noted earlier, individuals caring for both a child and adult were coded as missing.

Caregiving transitions/stability: Periods of change and stability in the provision of care over a caregiving episode were analysed in chapter eight. Data from waves 3, 5 and 7 were merged into the main datafile and hours of care was recoded as a dichotomous variable, coding care of 20 or more hours per week as 1 and less than 20 hours or no care as reference category. This variable was used to code transitions between waves 3 and 4, waves 5 and 6 and waves 7 and 8 in wide format. No care in either wave was coded as the reference category. Individuals not providing care in the first wave but caregiving in the second were coded as starting to provide care, coded 1. Those providing care in both waves were coded 2, continuous care. Those caregiving in the first wave but not in the second were coded 3, ceasing care (for instance, Sacco et al., 2022).

Caregiving duration: Duration of care was analysed in chapter eight. The variable was created using the sum of waves 3 to 8 in which care of 20 hours per week was reported. The variable ranged from zero to six waves of care but the majority of caregivers reported caregiving for two or fewer waves, therefore the final variable was coded 0 for the reference category never providing care of 20 hours per week; coded 1, care of 20 hours per week for only one wave, and 2, two or more waves of such care, similar to other authors (Lacey et al., 2018). The variable is not completely analogous to caregiving duration, as no caregiving history was available prior to first wave of entry into ELSA and the first wave used for all respondents was wave 3.

Caregiving location: Analyses in chapter nine focused on co-resident care provision as well as partner health, detailed below. Two care location variables were coded: one for waves 4, 6 and 8, and one for the COVID-19 data. For waves 4, 6 and 8, care location was derived from the question “*Does the person/people you care for live with you?*”. With no care as reference category, individuals who cared for someone outside their place of residence (non-resident care) were coded 1 and individuals caring for someone in the

same household (co-resident care) were coded 2. Those providing both co-resident and non-resident care were coded as providing co-resident care (Arber & Ginn, 1995). The suite of care questions included in the online survey differed from those in the main surveys. Three questions identified individuals providing co-resident care during the pandemic, coded 1 and those not providing co-resident care, reference category coded 0. Pre-pandemic co-resident caregivers were identified using the question, *“Just before the coronavirus outbreak began in February, did you look after anyone once a week or more?”*, followed by a question *“Did the person you cared for ... live with you or in another household?”*. Individuals who had stopped providing co-resident care since the pandemic were identified and recoded as not providing co-resident care if they responded, *“It has stopped”*, to a third question *“Has the amount of care you provide...in your household changed since the coronavirus outbreak?”*.

Partner health variables: in chapter nine, partner health variables were included in analyses to investigate their associations with sleep disturbance in the context of co-resident care and cohabiting couples. Only those partners aged 50 and over were included in analyses (620 observations were removed from waves 4, 6 and 8 during sample selection, see Figure 6.3 in the next chapter). Long-term conditions associated with sleep disturbance include cancer (Otto et al., 2019); coronary heart disease, measured by diagnosis of angina or myocardial infarction (Koyanagi et al., 2014; Poole & Jackowska, 2018; Smagula et al., 2016); lung disease (Koyanagi et al., 2014; Smagula et al., 2016), arthritis (including osteoarthritis) (Koyanagi et al., 2014; Poole & Jackowska, 2018) and neurological conditions. Neurological conditions, including diagnoses of Parkinson’s disease (Cupidi et al., 2012; Happe et al., 2002) and dementia (Gao et al., 2019; Webster et al., 2020) were aggregated due to low numbers of cases. Respondents were asked to confirm previously diagnosed heart and other conditions and to identify newly diagnosed conditions. These conditions were coded as 1 diagnosed (in a previous or current wave) or 0 not diagnosed. Correspondence with the ELSA team indicated an issue with the fed forward information from previous waves requiring re-coding of diagnosed condition information using responses from all waves, from wave 1 onwards, see Appendix B for a description of the process. General measures of partner physical health were the total number of diagnosed conditions and

number of activities of daily living, ADL difficulties (for instance, Floridi et al., 2021). Total number of difficulties with ADLs, were summed from responses to the question asking about difficulties with every day activities caused by physical, emotional, or mental health or memory problems. The variable range was 0 to 6 difficulties with dressing, walking across a room, bathing, eating, getting in and out of bed and using the toilet (Vlachantoni, 2019). ADLs were chosen rather than IADLs as these activities are likely to require more assistance and be critical to everyday functioning (Han et al., 2021). The variable was non-normal (wave 4: skewness 4.0 and kurtosis 21.9). Total number of health conditions were summed from responses to existing or newly diagnosed heart and other conditions. The variable ranged from 0 to 13 in the samples for each wave and had a longer right tail (wave 4: skewness 1.2 and kurtosis 4.9).

5.3.2 Covariates

Demographic, socioeconomic and health factors found to be associated with caregiving and sleep in the literature review sections 3.3 and 3.4, were added into multivariable analyses. The measurement of these variables is discussed below. In addition to these variables, a wave variable was included in each model, coded 4 (reference category), 6 or 8, to account for changes in sleep disturbance due to the passage of time. For instance, the slight increase in reporting sleep disturbance among men over the three waves (see chapter seven, Table 7.4).

Demographic variables: Respondent gender was used to stratify samples, coded 0 for men and 1 for women. Respondent age was included as a continuous variable, both in linear and quadratic form, to identify non-linear relationships with outcomes over time, range 50-99, except in wave 8 and COVID-19 wave 1 where the range was 52-99, as no replacement sample was collected in these waves. Marital status was included in all models, except couple analysis in chapter nine, as a three-category variable as only changes in the availability of a partner to provide care or be cared for were of interest: married or in a civil partnership (reference category); divorced, separated or never married coded as 1 and widowed, coded 2.

Socioeconomic variables: non-housing, non-pension equivalised wealth quintiles was included as an indicator well-suited to capturing lifetime socioeconomic status among older adults (Brandt et al., 2021), coded 0, highest wealth quintile to 4, lowest wealth quintile. Work status was included as a dichotomous variable indicating a respondent was in paid work or self-employed, coded 1, compared to not being in paid work (the reference category, coded 0). Education was included as a time-invariant variable as few individuals changed their education level over time. Education was included in multilevel models and logistic regression of COVID-19 data in chapter nine. In these models holding a university degree was the reference category coded 0, having intermediate level education coded 1 and having no qualification was coded 2, following other studies (Stoye, Zaranko, Shipley, Mckee, & Brunner, 2020).

Household variables: In chapter nine, household variables were included to adjust for factors common to couples at the household level and that may indicate alternative sources of care. Variables included non-housing wealth (coded as above), tenure, household receipt of informal and formal care, household size, presence of children living outside or within the household and joint care, following recent couple-level analyses of caregiver health (Bertogg & Strauss, 2020). Tenure was coded 1 for individuals who owned their property outright, 2 for those who had a mortgage or part-mortgage and 3, for those who were renting. Household receipt of formal care or informal care from a person other than a spouse was derived from respondent and partner responses to questions on receipt of paid and unpaid care to help with problems with moving around the house, washing, or preparing or eating a meal. Informal support from a child, friend, neighbour or relative other than a partner for any of these difficulties, or support for the same ADLs from paid individuals (privately paid help, local authorities, health visitors and others) was coded 1, otherwise no difficulties or no such care was coded 0. ELSA asks respondents whether they have children living in their household or outside the household. These questions were used to assess the presence of children. Those with no children, reference category, were compared to those with children living away from the respondent, coded 1, and those with at least

one child living with them, coded 2¹¹. Whether a couple provided joint care was included in descriptive analyses, using partner and respondent location and relationship of care responses to distinguish respondents not providing joint care, reference category, from those providing mutual care to their spouse, coded 1, and those providing joint care to a parent or parent in law in the same household, coded 2.

Health and physical activity: Analyses controlled for a range of respondent health variables that have been associated with sleep disturbance and previously been included in caregiver sleep studies. Moderate or severe pain was coded 1, no or weak pain, the reference category. Limiting illness included no illness as the reference category, non-limiting illness, coded 1 and limiting illness, 2. Physical inactivity was coded from questions asking respondents the frequency of sports or activity that were “*vigorous*” or “*moderately energetic*” coding moderate or vigorous activity more than once per week as 0 (reference category), and once or less per week as 1 (Poole & Jackowska, 2018). Self-rated health was included as an accurate predictor of overall health (Fayers & Sprangers, 2002; Jylha, 2009). Respondents were asked “*How would you rate your overall health?*” and responses of “*Good*” or better were coded 0, and “*fair*” or “*poor*” health coded 1. To capture depressive symptoms, the eight-question version of the Centre for Epidemiological Studies – Depression scale, CES-D (Radloff, 1977), was included in all analyses. The question item on restless sleep was excluded from calculating depression scale scores to remove shared variance with the sleep disturbance dependent variable (Jaussent et al., 2011; Poole & Jackowska, 2018; Skapinakis et al., 2013); an approach also used with other concepts closely allied to depression such as loneliness (Luo, 2021). Questions asking the respondent whether they “*enjoyed life much*” and were “*happy much of the time*” were reverse-coded, and a summary score computed (range 0-7). A dichotomous variable compared individuals reporting 3 or more symptoms (coded 1) with those reporting fewer than 3 symptoms (reference category) (Di Gessa et al., 2017). An alternate scoring method, scoring high

¹¹In the cross-sectional, multi-level analysis of couples, the response to this question differed in six couples (one individual responded to having a child in the household and one individual responded to having a child outside the household). This is likely due to having children from a different partner. For the analysis of couples, the response for both individuals in these six couples was recoded to having a child inside the household, as the presence of children in the household may affect sleep.

depressive scores as 4 and over (Coe & Van Houtven, 2009; Heger, 2017; Steffick, 2000) was not used with the shorter scale ranging from 0 to 7 symptoms.

COVID-19 survey covariates: Variables for gender, age, marital status, and self-rated health were coded in the same way as above¹². Limiting illness, tenure, non-housing wealth and partner ADL count were also coded as above but drawn from wave nine as no suitable questions were included in the shorter COVID-19 questionnaire. Total partner and individual health conditions were derived from previous waves including wave nine responses as detailed above and in Appendix B and updated with new conditions from the pandemic online survey using the question *“Thinking about what has happened since we last saw you, has a doctor ever told you that you developed a new health condition?”*. The dichotomous depressive symptoms variable was coded using only six symptoms instead of seven as detailed above, as the item on feeling sad was mistakenly excluded from the COVID-19 wave one survey until late in data collection (NatCen Social Research, 2020c). Descriptive statistics are provided for two pandemic-related variables, not included in multivariable models in chapter nine. To ascertain household shielding, respondents were asked *“In [April/last week] would you say you were... self-isolating...”*. Household shielding was coded as follows: 0 when both members of the couple did not shield in April or July; 1 when one person shielded and 2 when both partners shielded. Diagnosis of clinical vulnerability was derived from the question *“Have you been contacted by the NHS or your GP and advised that you are vulnerable and at risk of severe illness if you catch coronavirus...”* and coded 0 if neither person was diagnosed by a GP or other professional as clinically vulnerable to COVID-19, 1 if one person was considered clinically vulnerable and 2 if both partners were clinically vulnerable.

5.4 STATISTICAL APPROACH

This section describes the statistical methods employed in this research. In this first section, it addresses the rationale for the use of longitudinal data and panel models. In

¹² In the COVID-19 sub-study questionnaire, the self-rated health question also included reference to a specific timeframe *“In the past month...”*, but no other changes.

section 5.4.1, it describes fixed effects models, the main statistical approach used in the thesis. Alternative approaches: random effects and within-between random effects models are briefly discussed in section 5.4.2. Finally, in section 5.4.3, details are provided of the rationale for analytic choices, methods employed in descriptive analyses and analytic approach followed in each chapter.

5.4.1 Descriptive analyses

In chapter six descriptive statistics are presented for the cross-sectional samples of the main waves of data used in the thesis: waves 4, 6 and 8, which are subsequently used in chapters seven and eight for longitudinal analyses. Sample characteristics by gender and changes in sample characteristics across the three main waves of data were assessed. Characteristics of caregivers compared to non-caregivers, stratified by gender assessed differences in sleep disturbance and key covariates by caregiving hours, relationship to the care recipient and location of care. Similar analyses were conducted in chapter nine, by gender and of co-resident caregivers compared to non-caregivers, for the sample of couples from ELSA main waves and the COVID-19 sub-study. All analyses were weighted using the appropriate cross-sectional weight and analysed using Stata `svy`: suite of commands, except for analyses conducted on pooled waves of data, where no suitable weight was available¹³. In analysis of ELSA COVID-19 sub-study data, the longitudinal weight was used due to inclusion of several wave 9 variables, and household clustering and stratification variables applied, as recommended (NatCen Social Research, 2020c). Statistical differences were calculated using design-based F statistics for categorical variables and for continuous variables, t-tests from regression analysis were used as `svy`: does not support separate t-test or ANOVA analysis. In unweighted analysis of pooled data, Chi-squared tests were used for categorical variables and t-tests (two group comparisons) and ANOVA (three group comparisons) for continuous variables. Frequency and percentage of caregiving hours and relationship to the care recipient (chapter seven), caregiving transitions and durations

¹³ The samples used in analyses in this thesis included individuals who had not responded to all prior ELSA waves. Respondents only receive a longitudinal weight in ELSA if they responded in all of waves up to the wave in question, or in wave 8, all waves between wave 4 and wave 8 (NatCen Social Research, 2020a).

of care (chapter eight) and co-resident care (chapter nine) were calculated for the longitudinal samples.

5.4.2 Panel descriptive statistics

For each longitudinal sample, Stata code *xtdes* was used to assess the percentage of the sample responding to each combination of waves, see Table 7.1. The stability in sleep disturbance (and other variables) across waves is an important reason for using panel methods, but variables need to have sufficient variation for fixed effects models to run and estimate unbiased coefficients. In chapter seven, serial correlation in sleep disturbance across the three waves was assessed using tabulations of sleep disturbance and lags of two and four waves, see Table 7.3. Tabulation of lags of two waves for each caregiving variable were also run for each chapter, to identify the frequency of transitions in the data. Within and between variation in variables across waves were analysed using *xttab* (categorical) and *xtsum* (continuous). Sleep disturbance and the focal caregiving characteristic are included in the main text, for example, Table 7.4 and 7.5. Covariate statistics are presented in the Appendices.

5.4.3 Panel models

Overview of panel models

Panel models were used for most inferential analyses, as a suitable approach for modelling the longitudinal data required to address the research questions in this thesis. In relation to the research questions, longitudinal data has several advantages over cross-sectional data. First, cross-sectional data allows for the control of confounding factors in the relationship of interest that are measured and available in the data. However, all confounding factors are not always available or able to be measured and may not all be known (Wooldridge, 2020). These unobserved variables can cause bias in parameter estimates. Variables such as personality are rarely included in population-based data and individual differences in these characteristics can lead to bias in the estimation of covariates with an ordinary least square (or logistic) regression analysis. In longitudinal data, measurements for individuals over time can be used to control for time-constant sources of unobserved difference: individual-specific

heterogeneity (Andres et al., 2013). Second, cross-sectional data is collected at one point in time. With multiple waves of data, the investigation of change and direction of associations is possible (Andres et al., 2013). In this thesis, longitudinal data was used to analyse associations between caregiving characteristics (and partner health variables in chapter nine) and sleep disturbance within individuals, adjusting for the effect of measured confounding variables and removing unmeasured time-constant sources of difference between individuals, predominantly using fixed effects panel models. This approach partially addressed selection bias due to underlying differences between caregivers and non-caregivers. This was important as factors that may influence the decision to provide unpaid care, such as health or socioeconomic status are also associated with sleep disturbance and may bias the parameters estimated. The research investigated concurrent associations and assessed direction of association, as well as differences across a caregiving episode through measuring caregiving transitions and stability in consecutive waves (in chapter eight).

Panel models are appropriate for longitudinal data, where the data structure includes repeated observations nested within individuals, meaning the independence assumption for an ordinary least squares or logistic regression does not hold (Andres et al., 2013). In most analyses in the thesis, data were therefore structured in long format, by higher-level units: individual respondents, and lower-level units: observations of variables for an individual at each time point or wave (Bell & Jones, 2015). A general panel model can be described by equation 1 below:

$$Y_{it} = \beta_t + \beta_{it}X_{it} + \beta_iZ_i + v_i + e_{it} \quad (1)$$

Where Y_{it} is the outcome of interest for an individual, i , at a particular time point, t ; β_t is the intercept; β_{it} represents the coefficients for each time varying independent variable X , for each individual, i , at time t ; β_i represents the coefficients for each time-invariant independent variable Z ; and v_i and e_{it} are the error terms. The error term in a cross-sectional linear regression ϵ , is split into time-invariant unexplained variance associated with individual, i , (v_i), and time-varying unexplained variance (e_{it}).

In addition to the addressing the problem of unobserved heterogeneity between individuals, panel model approaches can be used to address serial correlation in responses by individuals across years of longitudinal data. When not accounted for, serial correlation in variables across waves of data can decrease the standard errors of the regression coefficients, potentially leading to type I errors (Andres et al., 2013). Three different panel models were considered for this research: fixed effects models (preferred), random effects models and within between random effects (WBRE) models. The next sections discuss the details of these models before presenting the rationale for choosing fixed effects models.

Fixed effects models

Fixed effects panel models focus on within-person change, differencing out time invariant error, v_i (and variables, Z_i), in equation 1 above, enabling the calculation of within-person change coefficients (Allison, 2009b). Effectively individuals are their own controls and coefficients estimated represent the effect of a change in status for a given individual (Allison, 2009b). To achieve this, for continuous dependent variables, fixed effects models centre all variables on their unit-specific mean, time-demeaning the variables (Andres et al., 2013). The equation for a fixed effects linear regression model is below (Bell & Jones, 2015):

$$(Y_{it} - \bar{Y}_i) = \beta(X_{it} - \bar{X}_i) + (e_{it} - \bar{e}_i) \quad (2)$$

Model covariates are as for equation 1 above, and additionally \bar{Y}_i , \bar{X}_i and \bar{e}_i are the unit-specific means for all time points of Y_i , X_i and e_i .

Fixed effects models assume unexplained individual variance, v_i , in the model may be correlated with covariates due to important omitted variables, ($\text{Corr}(v_i, X_{it}) \neq 0$). For instance, personality traits such as neuroticism or conscientiousness, may affect

propensity to be a caregiver or to experience sleep disturbance. Other assumptions are similar to those for ordinary least squares regression.

When the dependent variable is binary, a logit link function (the log odds ratio), $\text{Log} \left(\frac{p_i}{1-p_i} \right)$ is used to model a linear relationship between the dependent and independent variables, where p_i is the probability of $Y_{it}=1$. Regression coefficients are estimated accounting for the overall likelihood one individual has of reporting the response category of interest dependent on all time-varying covariates (conditioning on the number of $Y_{it}=1$ for each individual). This estimate is made through conditional maximum likelihood estimation (Allison, 2009b). The linear and logit approaches are similar and control for differences between individuals: person-specific heterogeneity, u_i (Andres et al., 2013).

Fixed effects panel models, whether logit or linear, therefore model change within individuals, having removed time-invariant known and unknown causes of variation (Andres et al., 2013). In this way, selection bias due to differences in the fixed characteristics of individuals (for instance among individuals who are caregivers compared to non-caregivers), can be removed (Gerlich & Wolbring, 2021). The fixed effects model approach has several limitations, however. First, the models do not allow the calculation of coefficients for known time-constant variables, such as gender or education, though they are controlled for (Andres et al., 2013). Second, models drop all instances of stability within the independent variables, reducing the analytic sample, statistical power and increasing the potential for sample bias (Collischon & Eberl, 2020). It is therefore important to check there is sufficient evidence of change within the independent variables, section 5.4.2 above described how this was done. Logit fixed effects models include an additional limitation, as for these models use only cases where the dependent variable changes over time to calculate coefficients, a consequence of maximum likelihood estimation, causing further reduction in sample size (Andres et al., 2013).

Alternative approaches: random effects and within-between random effects models

Two alternative panel model approaches that could be used instead of fixed effects models are random effects, RE, models and within-between random effects, WBRE, models. Both these models address the serial dependence inherent in longitudinal data with multiple measurements of individuals over time and allow for analysis of change. RE models differ in their treatment of unobserved heterogeneity in the data, while WBRE has been termed a hybrid of RE and FE models (Andres et al., 2013). RE models make a more stringent assumption about individual unexplained error, v_i , assuming it to be uncorrelated with model covariates ($\text{Corr}(v_i, X_{it}) = 0$), modelling both time invariant and time varying error as normally distributed variables. This means unobserved factors such as personality or genetic factors are assumed not to vary by model covariates. In contrast to fixed effects models, RE models allow time-constant predictors, such as gender, to be modelled and make use of the full range of data (Bell & Jones, 2015). Correlation between time-invariant error and model variables can be identified by testing the difference in regression coefficients for time-varying variables estimated with a fixed effects model and a random effects model, using a Hausman test (Andres et al., 2013). A large difference and significant Hausman test are often taken to mean the assumption of uncorrelated error for random effects models cannot be met and fixed effects models chosen instead (Andres et al., 2013). In fact, a positive Hausman test can indicate differing associations between individuals and within individuals over time, which can be modelled using WBRE models (Bell & Jones, 2015).

Rather than removing heterogeneity between individuals through fixed effects models, an alternative approach when differing within and between processes are suspected is to use WBRE models (Bell & Jones, 2015; Bell, Fairbrother, & Jones, 2019). The models make less exacting distributional assumptions about the unexplained between variance than random effect models, use the full range of data for the between coefficients and the same cases as fixed effects models for within coefficients (Bell & Jones, 2015). Modelling the unexplained variance at both levels of the model is done by time de-meaning the time-varying variables, calculating coefficients for the average deviation from the mean over time (within effect), and separately the coefficient for the group mean of each time varying variable (between effect) (Dieleman & Templin, 2014). In

doing so they provide estimates of both between effects for time-varying variables (the average for all individuals) and within effects for time-varying variables (average change within an individual over time) (Bell & Jones, 2015). See appendix B2 for RE and WBRE equations.

In addition to panel methods, caregiving research has also used other methods that address omitted variables and selection bias (Bom et al., 2018). However, each method has its limitations and panel methods were considered best suited to this research. For instance, instrumental variable models require a suitable instrument that follows stringent assumptions, being both correlated with the explanatory variable of interest but uncorrelated with other variables relevant to the outcome (Martens, Pestman, de Boer, Belitser, & Klungel, 2006). However, few factors meet the stringent assumptions and those that do often depend on a specific set of circumstances, limiting the circumstances of care that can be addressed and of comparison across studies (de Zwart et al., 2017). Propensity score matching matches a group of non-caregivers to caregivers using observed characteristics. It requires appropriate matching variables that capture the observed and unobserved differences relevant to both caregiving and the outcome of interest, a wide range of characteristics that are not always available (de Zwart et al., 2017). Transitions in caregiving cannot be modelled using this approach, important for the research questions in this thesis (Brimblecombe, Knapp, King, Stevens, & Cartagena Farias, 2020).

Rationale for choosing fixed effects models

In chapter seven, the models for the first analysis of caregiving hours and sleep disturbance were run for women and men using each of the three model types: fixed effects, random effects and within-between random effects (Andres et al., 2013). A Hausman test indicated coefficients for fixed and random effects models were different, though only among health variables, widowhood, and wealth quintiles, and not caregiving (results provided in Appendix Table D4). Fixed effects models were preferred for this reason to random effects models (Andres et al., 2013). Comparisons of data simulations across these models have shown fixed effects and within-between random effect models perform equally well in most situations and better than random

effects models, in terms of coefficient bias and efficiency (Bell & Jones, 2015). WBRE models were initially considered preferable, allowing estimates of caregiving coefficients for changing care within individuals and for care provision on average. However, fixed effects models were chosen as the primary statistical approach for the thesis rather than WBRE models for three reasons. First, no significant differences were found in within and between estimates of caregiving coefficients, but differences were found in other variables: for instance, widowhood and depressive symptoms (as noted above). This indicated that in the model there was no difference in the association with sleep disturbance of a within-person change in caregiving, compared to being a caregiver on average. WBRE models were therefore not necessary for the key explanatory variables of interest. Nevertheless, as there were significant differences in other variables, random effects models were also not appropriate. Second, no time-invariant variable was of specific interest, except gender, for which gender-stratified models could be specified. Third, WBRE models are computationally intensive (Bell and Jones, 2015). Fixed effects models were chosen therefore to provide a better indication of caregiving's unique effect on sleep disturbance, by excluding variation due to differences between individuals and focusing on change within individuals (Andres et al., 2013).

5.4.4 Overview of inferential analyses in chapters seven to nine

Inferential models

Most main analyses in the thesis used FE linear probability models (LPMs). Logit fixed effects models were initially run as the sleep disturbance dependent variable was dichotomous. However, these models drop cases without change in the dependent variable, leading to a large drop in sample size (see chapter seven, table 7.6). Linear probability models, LPMs, offer an alternative to logit models, where the dichotomous dependent variable is modelled using a linear regression model. In the context of fixed effects models, LPMs have the advantage over logit FE models of utilising the larger sample of both stable and changing sleep responses. They provide estimates of the probability of the outcome category of interest occurring, an easily interpretable magnitude of association (Mood, 2010). This can be viewed as an additional benefit

from these models, as odds ratios provide an indication of direction and significance of association but are more difficult to interpret than linear models (Breen, R., Karlson, & Holm, 2018; Mood, 2010)¹⁴. FE LPMs were run alongside logit FE models in chapter seven and instead of logit FE models in chapters eight and nine.

Several other statistical approaches were used in chapters eight and nine. In chapter eight, analyses of care transitions and sleep disturbance were modelled on both FE and RE LPMs. A Hausman test indicated differing within and between processes for several variables (wealth, widowhood, and health variables, as noted in the previous section), see Appendix E1. However, RE models were run to assess how results might change with inclusion of cases where continuous care was provided over more than two waves. RE and FE results did not differ substantially for caregiving coefficients and although RE models are presented, the discussion focuses on FE model coefficients. Research question 3 investigated change in sleep disturbance and this required a multinomial model as the dependent variable had four unordered categories, see section 5.3.1. Pooled multinomial logistic regression was carried out, following other studies (van de Straat et al., 2021). The model estimated relative risk of improving sleep disturbance, worsening sleep disturbance or stable sleep disturbance at both waves compared to having no sleep disturbance at either wave. In research question four, care duration was a time-invariant variable and would be differenced out of FE models; therefore, RE models analysed associations between care duration and sleep disturbance.

Chapter nine addressed associations among a sample of couples. Analysis of couples or dyad data poses specific methodological challenges due to shared variance across observations within a dyad (McMahon, Pouget, & Tortu, 2006). It is more complex still with longitudinal data as measurements are also statistically dependent over time (Andres et al., 2013). ELSA household identifiers change at each wave as individuals

¹⁴ Coefficients are standardised by the unexplained variance in the model, therefore, a change in odds between nested models is not only indicative of confounding or mediating relationships between explanatory variables, but also measures differences in unexplained variance (Breen, R. et al., 2018; Mood, 2010). Linear probability model coefficients differ little from average marginal effects estimated via a logit model (Breen, R. et al., 2018; Mood, 2010).

may change household. Household identifier can be cross-referenced across waves in the ELSA Index file, but at present this includes only waves 1 to 5 in publicly available data (NatGen Social Research, 2020a). For this reason, three level multilevel models could not be used, and a two-stage approach was taken to analyse co-resident care, partner health and sleep disturbance in chapter nine. Cross-sectional associations were investigated among couples using multilevel models, accounting for variation in sleep disturbance at the couple level. This was followed by longitudinal FE LPMs modelling observations over time, nested within individuals, including their partner's health characteristics as covariates. Cross-sectional multilevel models were used to be consistent with the literature investigating individuals within couples (Andres et al., 2013). However, the models are another tradition of hierarchical model and in two-level form the Stata commands for multilevel and random effects models (*mixed* and *xtreg, re*) give almost the same results with a data set nested as individuals nested within couples (Rabe-Hesketh & Skrondal, 2012). Of interest was the intraclass correlation coefficient, ICC (also estimated by random effects models), measuring residual correlation in sleep disturbance between individuals within couples (Snijders & Bosker, 2012). As with random effects models, the ICC is the proportion of variation in the model explained by variation at the group level and can be calculated unadjusted (unconditional) and following adjustment for model covariates (conditional) (Rabe-Hesketh & Skrondal, 2012; Snijders & Bosker, 2012), see Appendix B2 for equations. In the second half of the chapter, logistic regression was used to analyse sleep quality on co-resident caregiving and partner health characteristics using cross-sectional COVID-19 data. This analysis was carried out on sub-study wave 1, the available data at the time of analysis, though wave 2 has now been released for public use.

Sensitivity analyses were carried out in each chapter. In chapter seven, the effect of measurement level of sleep disturbance was tested by running an FE linear model using the continuous measure of sleep disturbance. Then an FE LPM constrained to the same sample used in the logit FE model was run, as suggested in recent methodological discussion (Beck, 2020). The treatment of missing data was assessed using the final model from FE LPMs for caregiving hours and caregiving relationship, re-run on imputed data (see below for details). In chapter eight, sensitivity analysis was

performed to assess whether an association found between sleep disturbance and ceasing care was due to health deterioration of the caregiver. ADL difficulties and total health conditions were added to the RE and FE LPMs for women. Sensitivity to measurement level of sleep disturbance and change in sleep disturbance was assessed using the continuous measurement of sleep disturbance and the final FE LPMs for the analysis of caregiving transitions and sleep disturbance were re-run using imputed data, as for chapter seven. In chapter nine, the final model from the longitudinal analysis of cohabiting couples was re-run using imputed data.

For each panel model, control variables similar to those used to calculate weights were added, and the analysis run unweighted. This avoided biased standard errors that may result if weights were applied to panel models (Andres et al., 2013). This was also the case for pooled multinomial logistic regression and multilevel models in chapters eight and nine. The relevant longitudinal weight was applied to logistic regression analysis of COVID-19 data, following guidance (NatGen Social Research, 2020c). FE LPM and linear FE models were calculated with cluster robust standard errors to adjust for heteroskedastic residuals and correlation in the idiosyncratic error, as fixed effects models assume error terms are constant and uncorrelated (Andres et al., 2013; Wooldridge, 2020). This was also the case for cross-sectional multilevel models in chapter nine, clustered by household number. The analyses in the thesis were carried out using Stata MP 15.0 and p values of less than 0.05 were considered statistically significant. However, bearing in mind recommendations from the American Statistical Association, p values were reported continuously where space allowed and confidence intervals were also reported where relevant (Wasserstein & Lazar, 2016; Wasserstein, Schirm, & Lazar, 2019).

Gender stratification

Most analyses in the thesis were run on gender-stratified data. Gender stratification allowed possible gender differences in the relationships between caregiving and sleep to be investigated. Chapter three and four demonstrated, from an empirical and theoretical perspective, why differences in caregiving and sleep disturbance associations may be expected. For instance, women are likely to carry out more care,

and to provide more intense care (Verbakel et al., 2017), they also report sleep disturbance more often than men (Arber et al., 2009). Further, they may experience or perceive care provision as more burdensome (Swinkels, van Groenou, De Boer, & van Tilburg, 2019) and may be more likely to act in ways that subsume their own sleep needs for the needs of others, due to gendered social roles (Hislop & Arber, 2003b). Gender stratification also enabled easier interpretation of the results, given the unusual distribution of the sex-specific sleep dependent variable.

Model covariates

For each analysis, covariates were added sequentially over models, with some variation across chapters. In chapters seven and eight, the first model in each table adjusted for demographic variables: age, age-squared and marital status, as well as wave to control for changes in sleep disturbance over time. Model two added socioeconomic and most health variables. Socioeconomic variables included work status and non-housing wealth quintile. Health variables included pain, activity level, limiting illness and self-rated health. Depressive symptoms was added separately from other health factors in the final model, following other studies (for instance, Grandner et al., 2012; Sacco et al., 2022), as depressive symptoms may be a mediator of caregiving and sleep associations as well as a confounding factor (Poole & Jackowska, 2018). Education was initially included in random effects models modelled in chapter eight, but reduced sample size available and was not included to maintain sample size for FE models (results did not differ with adjustment for education). Logistic and multilevel models included education. For analyses of partner data in chapter nine, models added respondent variables (demographic, work and health variables); followed by household variables (wealth, household size, presence of children and receipt of other sources of care) and finally partner health variables. Multilevel models also included an initial unadjusted model so an unconditional intraclass correlation coefficient could be calculated, the proportion of variance in sleep disturbance attributable to being in a couple (Snijders & Bosker, 2012).

Missing data

Missingness in the data occurs through attrition due to initial non-response and subsequent drop out from the study, as well as item and construct non-response within an individual's collected data (Newman, 2014). Loss of data due to missingness can introduce bias in coefficients, produce inaccurate standard errors and reduce the validity of results (Newman, 2014). In the ELSA data used in this thesis, attrition at older ages is partially compensated by collection of replacement samples and non-response is adjusted for with the use of weights (NatGen Social Research, 2020a). ELSA's response rates are high relative to comparable studies and additionally, little evidence of bias related to sample attrition has been found after removing non-response due to mortality (Banks, Muriel, & Smith, 2011). The level of item and construct missingness in the sample for the thesis was low overall, Appendix B1. A greater proportion of missingness related to missing waves. The fixed effects approach requires two complete waves of data from individuals. As sleep was measured only every other wave in ELSA, respondents were required to have complete data for at least two waves, four years apart (see chapter 6, section 6.4). Missingness occurs through three mechanisms. Missing completely at random, MCAR, does not depend on the value of any other factor and is completely random. Missing At Random, MAR, is missingness that depends on other covariates included in the regression models. Missing Not At Random depends on both observable characteristics within the data and also the level of the missing variable itself (Newman, 2014; Young, R. & Johnson, 2015). Each potential approach to handling missingness makes assumptions about the mechanism driving missingness. The main analyses in this thesis took a complete case approach, which incurs less bias than traditional methods of imputing missing values such as using the mean value (Allison, 2009a). Complete case analysis rests on the assumption of MCAR (Newman, 2014; Young, R. & Johnson, 2015). In simulations of fixed effect models with differing approaches to missing data, coefficients were underestimated using complete case analysis but had the same direction and significance as the true model (Young, R. & Johnson, 2015). MCAR is rare in observational studies, nevertheless, complete case analysis is a common approach to missing data (Young, R. & Johnson, 2015). In fixed effect models, reduced sample size due to loss of observations or individuals is likely to increase standard errors with subsequent wider ranging confidence interval around the estimates (Young, R. & Johnson, 2015). For these

reasons, sensitivity analyses were conducted using an alternative approach. Multiple imputation and full information maximum likelihood both assume missingness is MAR (Newman, 2014; Young, R. & Johnson, 2015) but only multiple imputation was available in Stata. Therefore, the consequences of dropping cases with missing data were tested in sensitivity analyses by re-running the final model from one set of analyses in each chapter after multiple imputation of the data, described below.

As most model variables were binary, multiple imputation with chained equations (MICE) was used to modelling the posterior predicted distribution of possible values for missing variables using observed values (White, Royston, & Wood, 2011). Imputation was carried out in wide format so values from previous waves could be included in the imputation; often the best predictors of plausible missing values (Young, R. & Johnson, 2015). Imputation was carried out on two samples, the first including variables for analyses in chapters seven and eight, where caregiving transitions were coded from waves 3, 5 and 7 first before data was imputed for available data from waves 4, 6 and 8. The second sample was for the longitudinal sample of partners in chapter nine. Data management to identify partners and code partner health variables was carried out prior to running the multiple imputation equation. Imputation equations used all variables included in the subsequently run regression models, except the wave variable. No auxiliary variables were included. Age-squared was computed manually and included in the imputation equation, following guidance (StataCorp, 2017c). Initially the posterior probability distributions used in the imputation equation were a logistic regression model for binary variables, a multivariate normal distribution for the few continuous variables, such as age and a multinomial logistic regression for categorical variables. However, perfect prediction was a problem, and the data was augmented, adding small numbers of observations (StataCorp, 2017c). The model then did not converge and predictive mean matching, was used for all variables, drawing from five nearest neighbours using command *pmm, knn(5)*. This command does not require a distribution to be specified and imputed values are drawn from the range of observed values for each variable (StataCorp, 2017c; White et al., 2011). Following imputation, descriptive statistics for the imputed datasets were examined to check that imputed values fell within the expected ranges (StataCorp, 2017c). Ten imputations were

initially run to check the code was correct. Once correct, ten cycles of twenty imputations were performed and a seed number, 1109, was used for reproducibility. The final model from one main analysis from each chapter was run on the imputed datasets, results combined using Stata's *mi estimate* commands (StataCorp, 2017c; White et al., 2011). Results were presented in the appendices and noted in each chapter.

5.5 CONCLUSION

This chapter outlined the reason for using data from the English Longitudinal Study of Ageing, ELSA, the variables, and the statistical methods used in analyses in empirical chapters six to nine. The following chapter provides descriptive statistics for the sample of individuals responding to waves 4, 6 and 8 with complete data on variables used in the study. Subsequent longitudinal analyses of caregiving and sleep disturbance continue in chapter seven, analysing caregiving hours and relationship; investigation of caregiving transitions and duration in chapter eight and considering possible relationships between co-resident caregiving, partner health and sleep among couples in chapter nine.

Chapter six – Descriptive statistics

6.1 INTRODUCTION

This thesis investigates how unpaid caregiving is associated with sleep disturbance, analysing different caregiving characteristics, transitions and stability and, among cohabiting adults, possible confounding by partner health. Caregivers have been found to differ significantly from non-caregivers across a range of different characteristics. The broad category of unpaid care itself masks differences between individuals providing care in differing circumstances, for instance, by location or hours of care (De Koker, 2009; Ramsay et al., 2013), as described in the Literature review, section 3.3. This chapter explores this heterogeneity among caregivers in the samples used in the thesis, and differences between caregivers and non-caregivers, providing a foundation to understand subsequent longitudinal analyses in chapters seven to nine. Sample selection and analyses in the chapter are described in section 6.2. In section 6.3, descriptive statistics stratified by gender are presented for the cross-sectional samples of waves 4, 6 and 8, the baseline samples for subsequent longitudinal analyses. Bivariate patterns of association between caregiving hours and sleep disturbance are described across the three waves of data in section 6.4 (caregiving relationship and co-resident care available in Appendix C). The sample selection criteria for each subsequent longitudinal sample are presented in section 6.5, along with differences in the characteristics of these samples compared to the dropped cases. A brief conclusion in section 6.5 ends the chapter.

6.2 SAMPLE AND ANALYTIC APPROACH

To illustrate the cross-sectional bivariate relationship between caregiving characteristics, sleep disturbance and key covariates, analyses in this chapter used wave 4 of the English Longitudinal Study of Ageing, ELSA, noting differences to the samples for waves 6 and 8. In ELSA wave 4, 11,050 individuals responded at interview. Individuals who did not have a valid weight, including partners, institutional interviewees and those no longer living in England and those who did not complete a

full or partial in-person interview, including proxy interviews were excluded (1,488 individuals). Core members with missing data from key covariates (423) were also excluded. The wave 4 sample for analyses included 9,139 individuals, 5,052 women and 4,087 men. Sample selection for waves 6 and 8 was carried out in the same manner, see Figure 6.1 at the end of the chapter. Item-level missing data was less than 0.1% in the remaining sample for each wave, except for caregiving variables, non-housing wealth quintiles and depressive symptoms which had between 0.7% and 2.2% missing responses dependent on variable and wave (Appendix Table C1). This level of missingness was similar to levels found in other analyses of ELSA data (for instance, Rippon & Steptoe, 2018). The higher level of missingness on caregiving variables was mostly due to the decision to code as missing individuals from the sample who provided care to both an adult and a child, as caregiving hours could not be disaggregated by age of, or relationship to, the recipient of care (a total of 268 individuals across the three waves).

Descriptive statistics for the sample at wave 4, stratified by gender, are presented (Table 6.1). Those for the unstratified sample for waves 4, 6 and 8 are presented (Table 6.2). Table 6.3 sets out the bivariate relationships between three caregiving characteristics (hours, relationship to care recipient and location of care) and sleep disturbance, stratified by gender, for each of waves 4, 6 and 8. Bivariate associations between caregiving hours and model covariates, stratified by gender are provided for wave 4 (Table 6.4). In Tables 6.1, 6.3 and 6.4, Pearson F-statistics (survey design-adjusted Chi-squared tests) were used to assess bivariate associations for categorical variables and t-tests for age. P values for the relevant test are indicated and a cross-sectional weight was applied. Table 6.2 analyses pooled data across waves, for which no appropriate weight was available¹⁵. For this table, p-values were estimated using Chi-squared and ANOVA tests.

¹⁵ ELSA's longitudinal weight variables give a weight to individuals responding to all of waves 1 to 8, or waves 4 to 8 (NatCen Social Research, 2020a); the pooled analysis in this chapter included individuals with non-responses at some of these waves.

6.3 SAMPLE CHARACTERISTICS

Sample characteristics for ELSA wave 4, stratified by gender are set out in Table 6.1. All differences between women and men discussed in this section were significantly different, except for self-rated health. Seven percent of the sample reported providing care for an adult; more women provided care (8%) than men (6%). Fifty percent of men who provided care did so for their spouse, while women predominantly cared for a parent or another individual (67%). Just over 40% of all care to adults was provided for 20 or more hours per week. Considering the sleep questions which contribute to the sleep disturbance dependent variable used in subsequent chapters, almost half of respondents reported waking up several times per night on three or more nights a week. Fewer individuals had problems with falling asleep (17%) and waking up tired (21%) on three or more nights per week. More women than men reported difficulties in sleeping three times per week across all aspects. Given this gendered pattern, the sleep disturbance dependent variable was distributed counterintuitively. Sleep disturbance was coded for individuals with a response in the highest sex-specific tertile for the sum of responses to the three sleep problem questions. The coding resulted in a lower proportion of women having sleep disturbance (22%) than men (30%), see Methodology section 5.3.

Demographic, socioeconomic and health characteristics were included as important possible confounding variables in the multivariable models in this thesis, given their importance in prior research, as discussed in the Literature review sections 3.3 to 3.5. Stable differences between individuals were differenced out using fixed effects models in chapters seven to nine (Allison, 2009b). The weighted sample had more women (55%) than men (45%), and the mean age was 66 years. Almost three quarters of men and just over 50% of women in the sample were married; as expected, a greater proportion of women were widowed (24%) than men (9%). Well documented differences in socioeconomic status by gender in later life were evident in the sample (Price, 2006). Fewer women than men had gained a qualification (63% compared to 75%) or were in paid work, while more women than men were in the lower two non-housing wealth quintiles. More than 70% of the sample reported experiencing good or better self-reported health (72%) and fewer than 3 symptoms of depression (82%).

Gender differences were found in the experience of depressive symptoms, limiting long-standing illness and pain, for instance, more women reported high depressive symptoms than men (21% versus 14%), and moderate and severe pain (32% versus 23%).

Table 6.1: Distribution of study variables in wave 4, by gender

	Women % N=5,052 (55.3%)	Men % N=4,087 (44.7%)	Total % N=9,139	P value
No care	91.9	94.0	92.9	<0.001
Caring for an adult (in last week and month)	8.1	6.0	7.1	
Under 20 hrs/wk	4.5	3.2	3.9	<0.001
20+ hrs/wk	3.6	2.8	3.2	
Spouse care	2.7	3.0	2.8	<0.001
Parent care	3.4	1.9	2.7	
Other care	2.0	1.1	1.6	
Has difficulty falling asleep				<0.001
Not in last month	51.5	70.8	60.5	
< once/week	13.3	9.7	11.6	
1ce or 2ce/week	13.5	8.8	11.3	
3+ times/week	21.6	10.7	16.5	
Wake up several times at night				<0.001
Not in last month	21.2	27.0	23.9	
< once/week	9.8	10.6	10.2	
1ce or 2ce/week	16.9	17.1	16.9	
3+ times/week	48.9	45.2	48.9	
Wake up feeling tired and worn out				<0.001
Not in last month	44.8	55.2	49.7	
< once/week	15.1	14.3	14.7	
1ce or 2ce/week	16.3	13.4	15.0	
3+ times/week	23.7	17.0	20.6	
Sleep disturbance				<0.001
Low disturbance	77.7	69.5	73.9	
High disturbance	22.3	30.5	26.1	
Sleep disturbance, (continuous), mean (se)	2.41 (0.01)	2.11 (0.01)	2.27 (0.01)	<0.001
Married	58.3	73.5	65.4	<0.001
Sep/div/never married	18.1	17.5	17.8	

Widowed	23.5	9.0	16.7	
Mean age (SD)	66.3 (0.18)	64.8 (0.17)	65.6 (0.12)	<0.001
Degree	11.6	20.4	15.7	<0.001
Below degree	51.3	54.2	52.7	
No qualification	37.0	25.3	31.5	
Not in paid work	60.7	48.4	54.9	<0.001
In paid work	39.3	51.6	45.1	
Owns home	62.4	59.5	61.0	<0.001
Mortgage	18.7	23.9	21.2	
Renting	18.9	16.6	17.8	
Highest wealth quintile	18.3	22.1	20.1	<0.001
Second highest	19.2	21.3	20.2	
Middle quintile	20.2	20.0	20.1	
Second lowest	21.8	17.7	19.9	
Lowest wealth quintile	20.5	18.9	19.7	
Self-rated health				0.2
Good or better	71.7	73.1	72.4	
Fair or poor	28.3	26.9	27.6	
Depressive symptoms (no sleep)				<0.001
Less than 3	78.8	86.0	82.2	
3+ symptoms	21.2	14.0	17.8	
No long-standing illness	45.4	47.3	46.3	<0.001
Non-limiting illness	18.5	20.8	19.6	
Limiting illness	36.1	31.9	34.1	
No/weak pain	67.5	76.7	71.8	<0.001
Moderate/severe pain	32.5	23.3	28.2	
Moderate/vigorous activity once per week	56.5	65.8	60.9	<0.001
Once a week or less	43.5	34.2	39.1	

Notes: cross-sectional weight applied; significance tests: design-based F statistics and t-tests (age); source: ELSA, wave 4; author's own calculations

6.3.1 Change in sample characteristics over waves 4, 6 and 8

Characteristics of the sample across the three key waves are displayed in Table 6.2.

Weighted percentages and means are provided for each wave. Statistical significance of changes over the three waves was calculated unweighted using Chi-squared and ANOVA

(age) tests, as no suitable weight was available for pooled data, see Methodology section 5.4.1. No significant differences in the percentage of caregivers or individuals reporting sleep disturbance were found across the waves. Among other variables, many of the changes in unweighted sample characteristics might be expected with panel ageing and through the impact of panel attrition, in addition to the inclusion of refreshment samples. Weights accounted for non-response for sample subgroups against population estimates including age by sex and variables associated with non-response at each wave, for instance, marital status and socioeconomic status such as education and housing tenure (Breedon et al., 2018; Bridges et al., 2015; Cheshire et al., 2012). Adjustment with weights reduced differences across the waves related to these variables. For instance, in unweighted data, the mean age of the sample increased from 66 years in wave 4 to 70 years in wave 8 (not shown). Adjusted with weights, no age differences were seen except for wave 8 where there were no 50- or 51-year-olds (no replacement sample was added in wave 8). Weights also adjusted for the smaller number of respondents at each wave in the lowest wealth quintile. Adjustment reduced differences in paid work, limiting illness and activity levels. For instance, the unweighted percentage of individuals reporting being retired and having limiting long-standing illness increased significantly over the waves, as expected with sample ageing. Once weighted, the percentage of retired individuals and individuals with no limiting illness did not differ markedly across the waves.

Table 6.2: Percentages and variation in sample characteristics over waves 4, 6 and 8

Variable	Weighted percentage of sample/mean (se)			Unweighted P value
	Wave 4 N=9,139	Wave 6 N=8,330	Wave 8 N=6,661	
No care	92.9	93.6	92.9	0.2
<20 hours	3.9	3.3	3.9	
20+ hours	3.2	3.1	3.1	
Low sleep disturbance	73.9	73.9	72.4	0.5
High sleep disturbance	26.1	26.1	27.6	
Mean age	65.6 (0.12)	65.5 (0.15)	66.7 (0.19)	<0.001
Men	44.7	47.3	47.7	0.6
Women	55.3	52.7	52.3	

Married	65.4	65.0	64.2	0.001
Separated/div	17.8	21.1	23.1	
Widowed	16.7	13.8	12.7	
Highest wealth	20.1	20.3	20.0	0.1
2 nd highest	20.2	20.1	20.0	
Middle	20.1	19.6	19.9	
2 nd lowest	19.9	19.7	20.0	
Lowest wealth	19.7	20.3	20.1	
Not in work	54.9	54.8	56.0	<0.001
In paid work	45.1	45.2	44.0	
Good or better health	72.4	72.8	73.3	0.2
Fair or poor health	27.6	27.2	26.7	
Depressive symp <2	82.2	83.4	84.4	0.001
3+ symptoms	17.8	16.5	15.6	
No pain	71.8	71.2	71.6	0.1
Moderate /severe pain	28.2	28.8	28.4	
No illness	46.3	47.4	46.5	0.04
Non-limiting ill	19.6	18.7	20.4	
Limiting illness	34.1	33.9	33.1	
Mod/vig activity >1/wk	60.9	63.1	64.5	0.6
Once/ week or less	39.1	36.9	35.4	

Notes: relevant cross-sectional weights applied; significance tests: unweighted Chi-squared tests and ANOVA (age); ELSA waves 4, 6 and 8; author's own calculations

6.4 NON-CAREGIVERS AND CAREGIVERS (BY HOURS, RELATIONSHIP, AND LOCATION OF CARE)

Table 6.3 presents the percentages of women and men reporting sleep disturbance (categorised as the highest sex-specific tertile) by caregiving characteristics across waves 4, 6 and 8. Characteristics include caregiving hours per week, relationship to the care recipient and location of care, compared to non-caregivers. Appendix Table C2 provides similar statistics for sleep disturbance measured continuously. Demographic, socioeconomic and health characteristics of non-caregivers, caregivers providing less than 20 hours of care per week and those caring for 20 or more hours of care per week

in wave 4 are presented in Table 6.4, stratified by gender. Similar statistics separating caregiving by relationship and by location are presented in Appendix Tables C3 and C4.

Table 6.3 provides the pattern of sleep disturbance by caregiving hours, relationship, and location across waves 4, 6 and 8. Contrary to expectations, no association with sleep disturbance (highest sex-specific tertile) was found for any caregiving characteristic at the three waves among women. However, among men, bivariate relationships were found between care provision and sleep disturbance: larger percentages of men providing longer hours of care and co-resident care reported sleep disturbance compared to non-caregivers, in waves 6 and 8. For instance, 50% of men providing 20 or more hours of care per week reported sleep disturbance, compared to 30% of non-caregivers in wave 6. Appendix Table C2 provides the same statistics when sleep disturbance was measured continuously. Measured continuously, greater sleep disturbance was found among individuals caregiving for 20 or more hours per week, providing spouse care and co-resident care in waves 4 and 6 (women) and waves 6 and 8 (men). For instance, mean sleep disturbance score for women caregiving 20 or more hours per week was 2.7 (standard error: 0.1) compared to 2.4 (se: 0.01) in wave 4 (Table C2).

Table 6.4 presents demographic, socioeconomic and health characteristics of caregivers and non-caregivers by hours of care per week and gender, for wave 4. Most care for less than 20 hours per week was provided non-residentially (76% among men and 86% among women), while longer hours of care, 20 or more hours per week, was predominantly provided within the same household, co-resident care. Women were more likely than men to provide longer hours of care outside the home (32% of women provided 20 or more hours per week for a non-resident recipient compared to 12% of men) and to relatives other than their spouse (41% of women versus 20% of men). Caregivers were more likely to be married than non-caregivers among both women and men. Female caregivers, irrespective of hours, were significantly younger on average than non-caregivers. Men caring for over 20 hours per week were significantly older (69 years) than non-caregivers (65 years). Both women and men caring for less than 20 hours per week were more likely to have a qualification, be in paid work and have a

mortgage; and fewer were in the lowest two wealth quintiles, compared to non-caregivers. For instance, 46% of women non-caregivers were in the two lowest wealth quintiles compared to 32% caregiving for less than 20 hours per week. Individuals providing care for shorter hours also reported being in better health than non-caregivers or caregivers providing 20 or more hours of care. For instance, women caregiving for less than 20 hours per week were less likely to experience pain (23%) or be in fair or poor health (14%) than non-caregivers (33% and 29% respectively). There were few differences in socioeconomic or health characteristics between women caring for 20 or more hours per week and non-caregivers. In contrast, men caring for 20 or more hours per week were more likely to be out of paid work, have no qualification, and report wealth in the lowest two wealth quintiles than male non-caregivers and men caregiving for fewer hours per week. A higher proportion of these men had poorer self-rated health (42%) and limiting illness (44%) than non-caregivers (27% and 32% respectively).

Characteristics of caregivers by relationship to the care recipient (Appendix Table C3) and by care location (Appendix Table C4), indicated men and women providing care to a parent or providing non-resident care were younger than other caregivers and non-caregivers, more likely to be in paid work, to be in higher wealth quintiles and to have better physical and mental health. Similar patterns have been found in other studies (de Klerk et al., 2021; De Koker, 2009). Individuals providing care to someone other than a parent or spouse were also healthier than non-caregivers and spouse or co-resident caregivers but older and less wealthy than parent caregivers. Characteristics of spouse and co-resident caregivers were similar. Spouse and co-resident caregiving men were older than other groups and less healthy. Both women and men spouse and co-resident caregivers were more likely to be in lower wealth quintiles. These differences mostly accord with those found in the literature review of factors related to care provision (de Klerk et al., 2021; De Koker, 2009). Differences by gender not indicated by the literature review were found among men and women caregivers providing 20 or more hours care per week, co-resident care and spouse care, where men but not women were less healthy and had lower socioeconomic status than non-caregivers. This may be related to these male caregivers being older and therefore less likely to be in paid

work and in poorer health, while women look after a wider range of individuals within their home and for longer hours. These differences between different sub-groups of caregivers and non-caregivers are important in subsequent analyses. Characteristics that are stable across years are differenced out of models and those that vary with time are adjusted for in analyses.

Table 6.3 Sleep disturbance by caregiving characteristics (percentages), gender, and wave

	Care intensity			P value	Relationship of care			P value	Location of care		
	No care	Care <20 hrs/wk	Care 20+ hrs/wk		Spouse care	Parent care	Other care		Non-resident care	Co-resident care	P value
Women											
<u>Wave 4</u> N=5,052											
Low sleep disturbance	77.9	79.1	71.6		72.2	77.2	78.1		78.1	72.2	
High sleep disturbance	22.1	20.9	28.4	0.13	27.8	22.8	21.8	0.50	21.9	27.8	0.25
<u>Wave 6</u> N=4,626											
Low sleep disturbance	78.0	78.6	71.6		68.5	80.6	78.2		78.5	71.5	
High sleep disturbance	22.0	21.4	28.4	0.19	31.5	19.4	21.8	0.08	21.5	28.5	0.19
<u>Wave 8</u> N=3,733											
Low sleep disturbance	77.4	75.7	80.2		79.5	73.3	80.8		78.6	76.3	
High sleep disturbance	22.6	24.3	19.8	0.80	20.5	26.7	19.2	0.78	21.4	23.7	0.94
Men											
<u>Wave 4</u> N=4,087											
Low sleep disturbance	69.7	65.0	68.0		65.5	65.6	70.4		65.5	67.2	
High sleep disturbance	30.3	35.0	32.0	0.53	34.5	34.4	29.6	0.71	34.5	32.8	0.57
<u>Wave 6</u> N=3,704											
Low sleep disturbance	70.0	72.3	50.2		59.8	57.8	72.9		71.7	55.6	
High sleep disturbance	30.0	27.7	49.8	0.001	40.2	42.2	27.1	0.08	28.3	44.4	0.01
<u>Wave 8</u> N=2,928											
Low sleep disturbance	67.8	61.6	43.9		50.2	56.4	52.0		63.4	44.5	
High sleep disturbance	32.2	38.4	56.1	0.01	49.8	43.6	48.0	0.06	36.6	55.5	0.01

Notes: relevant cross-sectional weights applied; significance tests design-based F-statistics. ELSA waves 4, 6 and 8; author's own calculations

Table 6.4 Characteristics by caregiving hours and gender (percentages), wave 4

	Women, N=5,052 (55.3%)			P value	Men, N=4,087 (44.7%)			P value
	No care N=4,631 (91.7%)	<20 hrs/wk N=238 (4.7%)	20+ hrs/wk N=183 (3.6%)		No care N=3,843 (94.0%)	<20 hrs/wk N=126 (3.1%)	20+ hrs/wk N=118 (2.9%)	
Caregiving								
Non-resident care		86.0	28.0	<0.001		76.4	13.5	<0.001
Co-resident care		14.0	72.0			23.6	86.5	
Spouse care		13.2	58.6	<0.001		22.6	80.3	<0.001
Parent/-inlaw care		49.4	32.2			49.5	12.1	
Other care		37.3	9.2			27.8	7.7	
Sleep disturbance								
Low disturbance	78.0	79.1	71.6		69.7	65.0	68.0	
High disturbance	22.0	20.9	28.4	0.1	30.3	35.0	32.0	0.5
Married	56.8	70.2	81.3		72.9	81.3	83.9	
Never married/divor/sep	18.2	20.6	12.9		17.6	15.6	15.4	
Widowed	24.9	9.2	5.9	<0.001	9.5	3.1	0.7	0.003
Mean age (SD)	66.7 (0.19)	60.3 (0.52)	63.9 (0.65)	<0.001	64.8 (0.17)	60.9 (0.76)	68.8 (1.07)	<0.001
Not in paid work	61.8	40.2	58.1		49.0	18.5	60.1	
In paid work	38.2	59.8	41.9	<0.001	51.0	81.5	39.9	<0.001
Owns home	62.4	61.1	62.2		59.5	59.0	60.9	
Mortgage	18.3	29.4	15.9		24.0	34.4	11.4	
Renting	19.2	9.4	21.9	<0.001	16.6	6.6	27.7	<0.001
Highest wealth quintile	18.2	21.3	17.2		22.0	31.4	14.7	

Second highest	19.0	25.2	16.4		21.4	23.7	14.0	
Middle quintile	19.9	25.2	20.6		20.0	21.2	20.1	
Second lowest	22.1	16.6	21.9		17.7	11.4	25.5	
Lowest wealth quintile	20.8	11.7	24.1	0.007	18.9	12.3	25.7	0.006
No long-standing illness	45.1	51.9	44.8		47.3	56.4	38.9	
Non-limiting illness	18.5	21.1	14.2		20.8	23.8	17.3	
Limiting illness	36.4	26.9	41.0	0.03	31.9	19.7	43.8	0.005
No/weak pain	67.2	76.9	64.4		76.7	80.8	71.1	
Moderate/severe pain	32.8	23.1	35.6	0.009	23.3	19.2	28.9	0.2
Moderate/vigorous activity								
Once per week	55.6	69.9	62.3		65.8	73.8	57.8	
Less than once/wk	44.4	30.1	37.7	<0.001	34.2	26.2	42.2	0.04
Self-rated health								
Good or better health	71.1	85.9	71.4		73.0	88.2	57.6	
Fair or poor health	28.9	14.1	28.6	<0.001	27.0	11.8	42.4	<0.001
Depressive symptoms, (no sleep item)								
Less than 3	78.5	84.9	77.1		86.0	89.1	82.3	
3+ symptoms	21.5	15.1	22.8	0.07	14.0	10.9	17.7	0.4

Notes: relevant cross-sectional weights applied. Significance tests design-based F statistics (categorical variables) and t-tests (age). ELSA wave 4; author's own calculations

6.5 SAMPLE DIFFERENCES ACROSS CHAPTERS

Each of the subsequent longitudinal analysis chapters in this thesis used a different sample according to the needs of the research questions and models, summarised in Figures 6.1 to 6.4 to follow. Comparison of each sample to the dropped cases showed significant differences which have implications for interpreting the results. The sample for chapter seven, which investigates associations between caregiving hours, relationship to the care recipient and sleep disturbance, included all core members in the cross-sectional samples for waves 4, 6 and 8 with two or more waves of complete data. The dropped cases were less likely to be in paid work, more likely to be in the lowest two wealth quintiles and to have poorer health (pain, limiting illness, fair or poor self-rated health and depressive symptoms). In chapter eight, which assesses caregiving transitions, care duration and sleep disturbance, individuals who did not have two waves of caregiving transitions/stability¹⁶ were dropped from the sample used in chapter seven. Dropped cases were more likely to be younger, widowed, in the lowest two wealth quintiles and have poor health. In the samples for both chapter seven and chapter eight, selection to the sample was not associated with caregiving hours and only in chapter eight did sample individuals have greater odds of having sleep disturbance. The sample for chapter nine, where associations between co-resident caregiving, partner health and sleep disturbance are investigated, comprised cohabiting individuals who had two or more waves of complete data, including partner health variables¹⁷. Item level missingness is noted in Appendix Table C1. A greater proportion of each sample was dropped due to wave non-response resulting in less than two waves of complete data, than from item level missingness. For instance, in wave 4, 423 individuals with valid weights were dropped due to incomplete data and a further 1,940 were dropped due to having only one wave of complete data. The requirement for individuals in the longitudinal samples to have complete data from two waves four years apart was demanding. Results from chapters 7, 8 and 9 may be less representative of individuals of lower socioeconomic status and poorer health, factors associated with being dropped from the longitudinal samples.

¹⁶ Caregiving transitions were coded for consecutive waves: wave 3 to wave 4, wave 5 to wave 6, or wave 7 to wave 8.

¹⁷ For partners aged 50 and over.

Figure 6.1 Sample selection for chapters six and seven

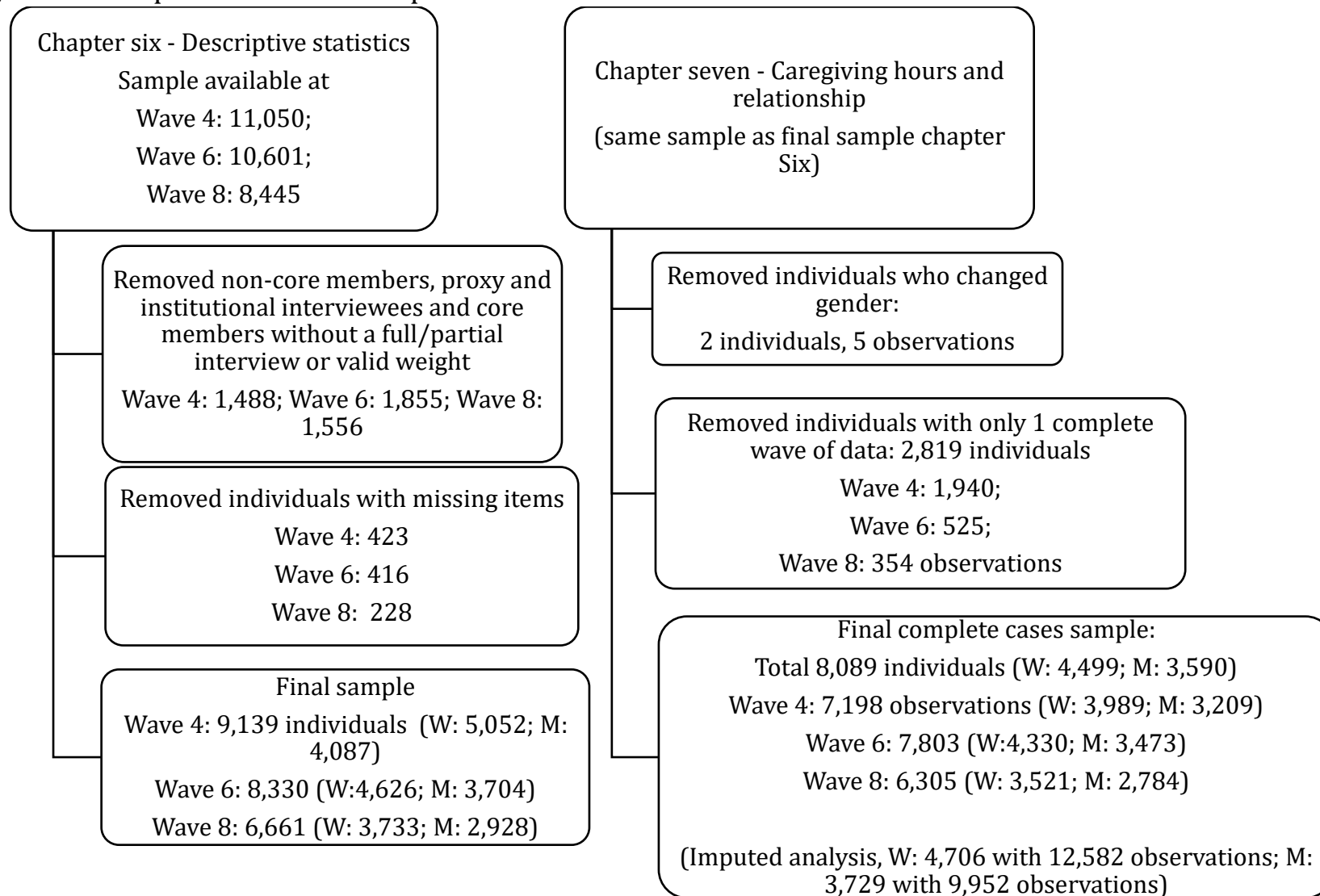


Figure 6.2 Sample selection for chapter eight

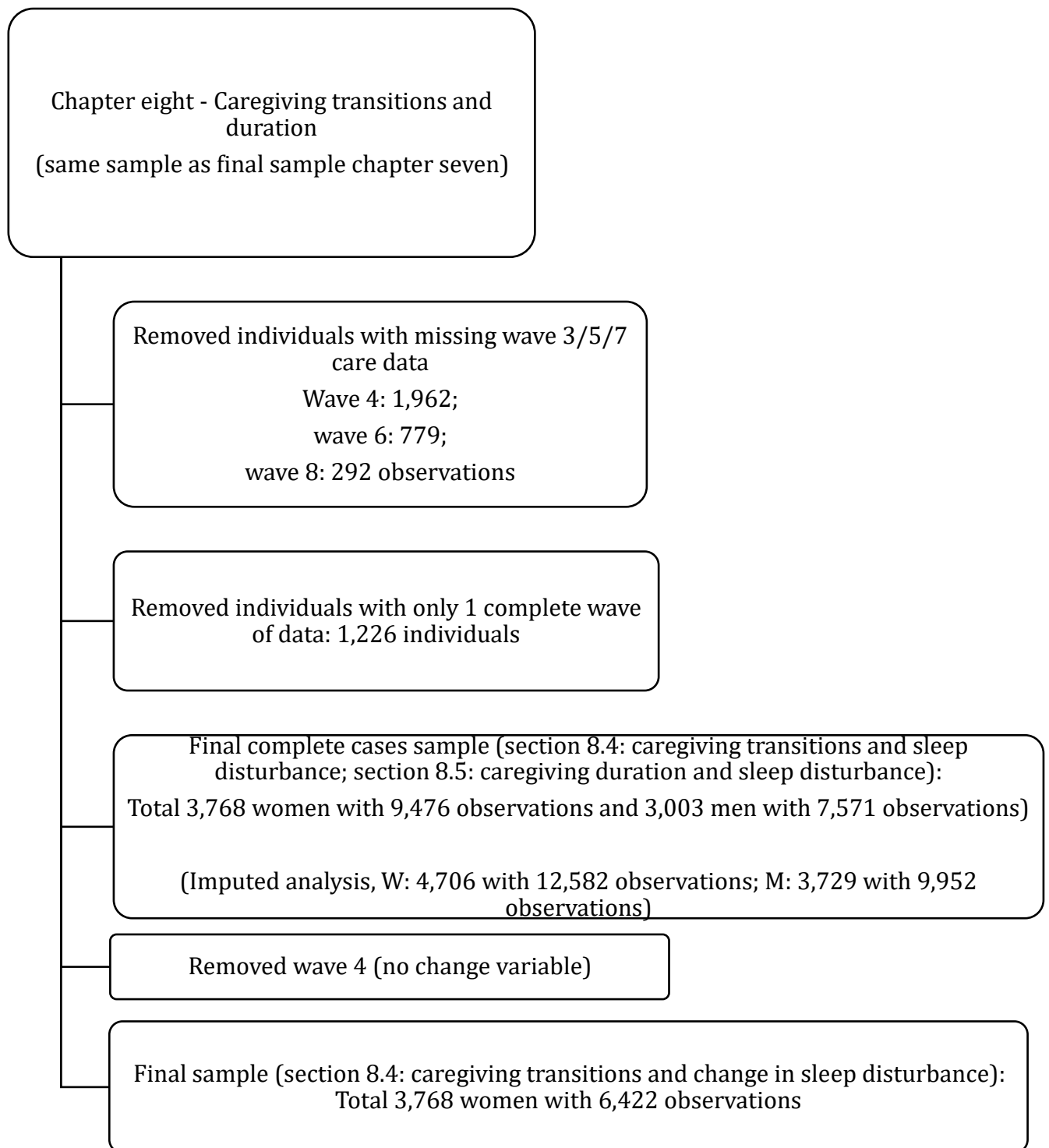


Figure 6.3 Sample selection for chapter nine ELSA main waves

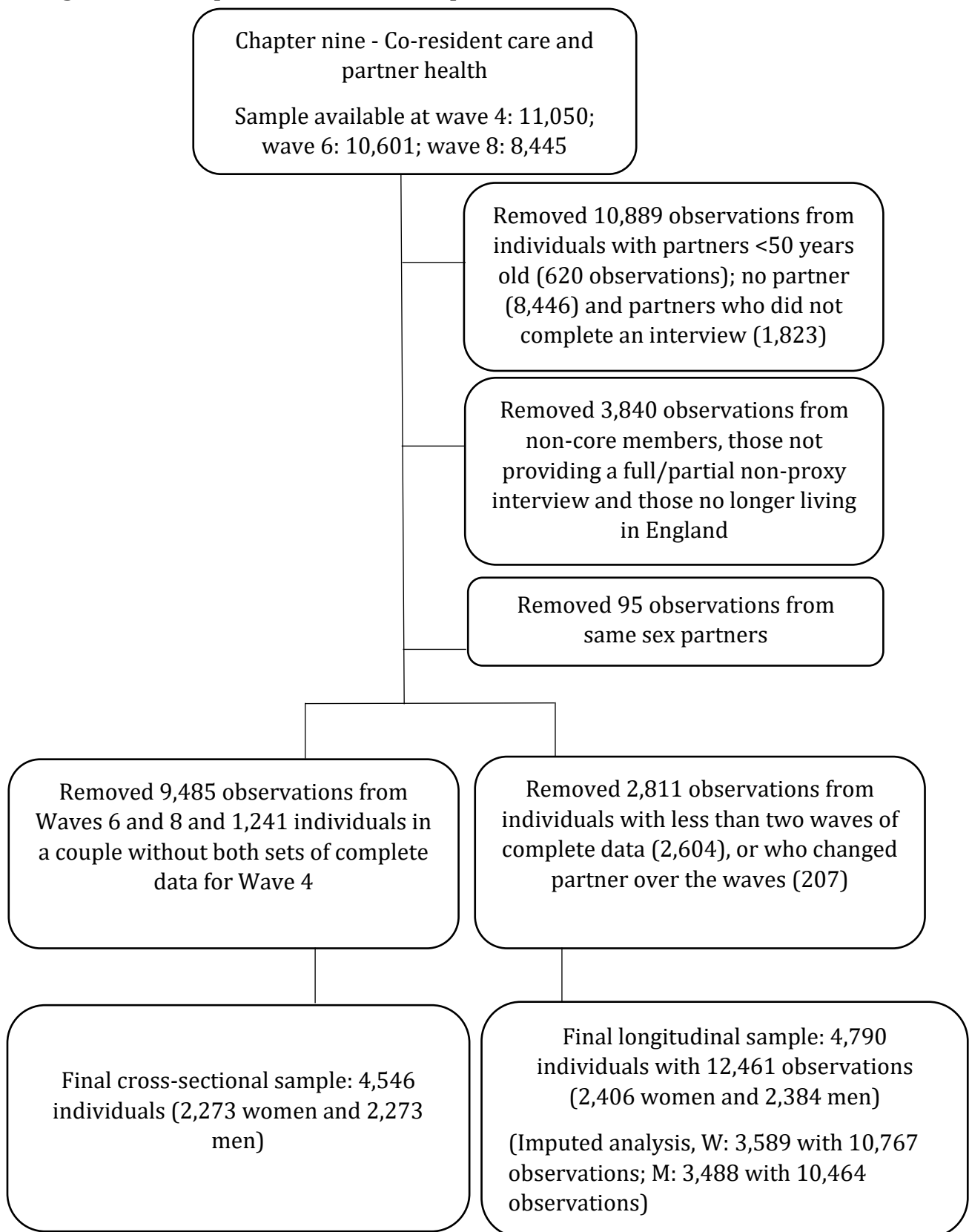
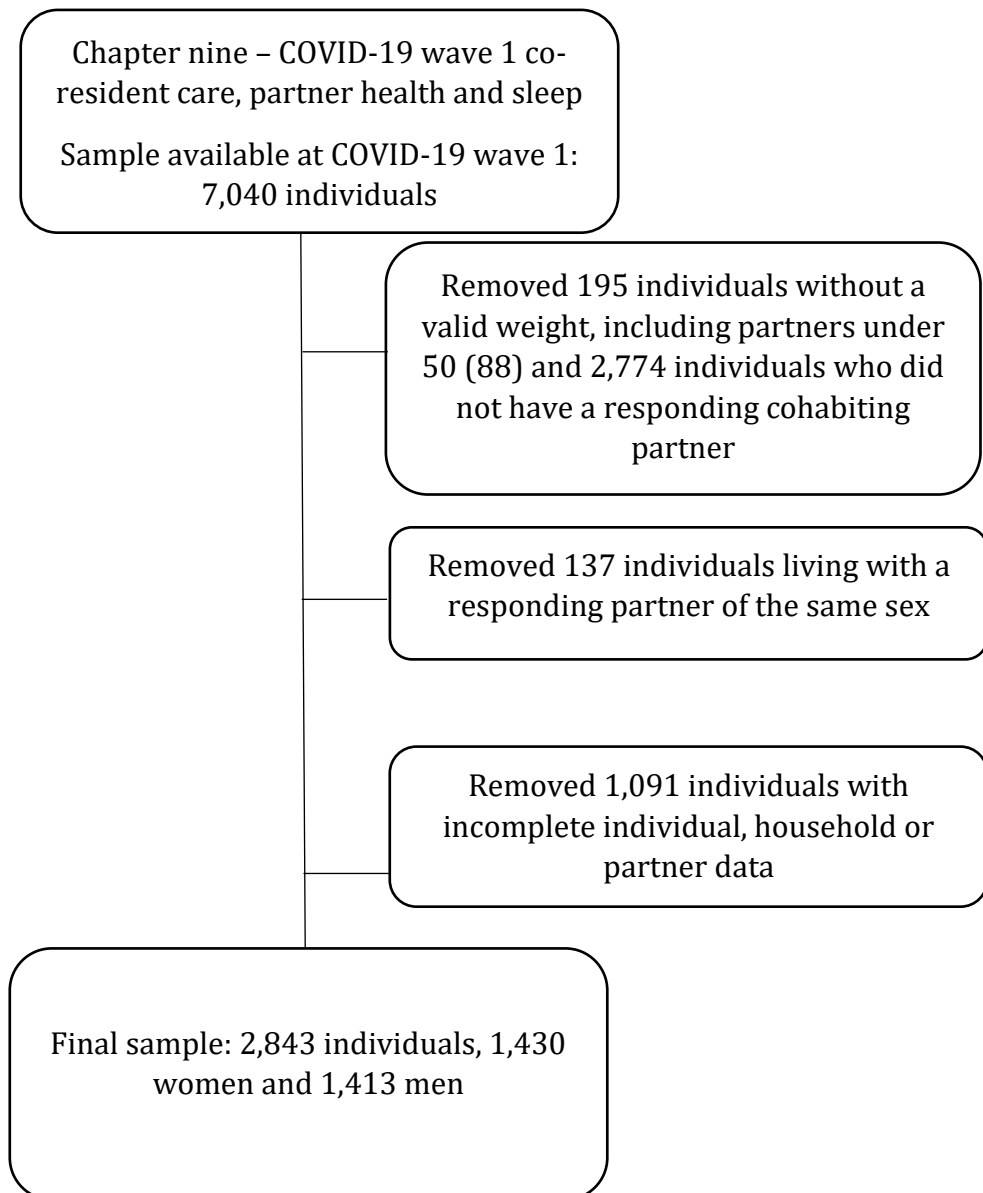


Figure 6.4 Sample selection for chapter nine COVID-19 sub-study wave 1



6.6 CHAPTER SUMMARY

This chapter presented descriptive statistics for the cross-sectional sample of ELSA waves 4, 6 and 8, the waves from which longitudinal samples in chapters seven, eight and nine were drawn. Differences were found in the demographic, socioeconomic and health characteristics of caregivers compared to non-caregivers as expected from the Literature review, section 3.3. For instance, women and men caregiving for less than 20 hours per week, providing non-resident or parent care were more likely to be younger, socioeconomically advantaged and in good health compared to non-caregivers. Women and men caregiving for 20 or more hours per week, providing spouse or co-resident care were more likely to be socioeconomically disadvantaged and men more likely to have poorer health than non-caregivers. Patterns of sleep disturbance differed by gender. As expected, overall, women reported more individual sleep problems than men, however, due to the method of coding, women had lower levels of sleep disturbance than men, when coded as the highest sex-specific tertile. In relation to caregiving, among men, longer hours of care and co-resident care were associated with sleep disturbance in waves 6 and 8. Similar differences were found among women when sleep disturbance was measured as a continuous, but not binary, variable. Sensitivity analyses in subsequent chapters assessed if associations changed when sleep disturbance was measured continuously. Sleep disturbances have been associated with demographic characteristics, measures of lower socioeconomic status and poor health (for instance, Arber et al., 2009; Fatima et al., 2020; van de Straat & Bracke, 2015). Differences in these characteristics between caregivers and non-caregivers is one justification for the use of fixed effects models in longitudinal analyses. FE models provide a better indication of caregiving's unique association with sleep disturbance by excluding time-invariant differences between individuals and controlling for time-varying changes in these factors. Although few bivariate differences in sleep disturbance were found by caregiving characteristics were found, subsequent chapters assess the extent to which differences in sleep disturbance may arise with changes in caregiving, using individuals as their own controls. Chapter seven addresses caregiving hours and the relationship to care recipient. Chapter eight considers whether transitions and stability in care, or care duration are associated with sleep disturbance, and chapter nine investigates co-resident care and partner health among couples.

Chapter seven - Caregiving hours, relationship of care and disturbed sleep

7.1 INTRODUCTION

This chapter examines whether caregiving hours or the relationship to the care recipient are associated with sleep disturbance. Analysis is guided by the stress process framework, where characteristics more likely to be experienced or perceived as stressful may result in consequences for health, with this thesis focusing on potential consequences for sleep (Lo Martire et al., 2020; Pearlin et al., 1990). The chapter adds to the literature on caregiving and sleep among mid- and late life adults by analysing caregiving hours per week using a cut-off point previously associated with poorer health outcomes: care of 20 or more hours (Bom & Stöckel, 2021; Hirst, 2005; Ramsay et al., 2013). Further, it analyses relationship to the care recipient (spouse, parent/parent-in-law or other relation or friend), a factor not yet addressed in the longitudinal population-based caregiver sleep literature. The chapter investigates the following research question,

Research question 1: How are caregiving hours per week (less than 20 hours per week and 20 or more hours per week) and relationship to the care recipient (spouse, parent/in-law or other) longitudinally associated with disturbed sleep among women and men?

Section 7.2 describes the samples and the analytic approach taken. Section 7.3 explores how much sleep disturbance and caregiving variables change over time in the longitudinal sample and how much within individual and between individual variation contributes to overall variation. This preliminary analysis confirms the presence of change in the variables, a requirement of fixed effects models. Results of longitudinal analyses of caregiving characteristics and disturbed sleep are presented in sections 7.4 (caregiving hours) and section 7.5 (caregiving relationship). Section 7.6 summarises the key findings and provides an interpretation of the results, concluding the chapter.

7.2 SAMPLE AND ANALYTIC APPROACH

The longitudinal sample for analyses in this chapter included individuals with two complete waves of data from waves 4, 6 and 8 of ELSA. This included 8,089 individuals (4,499 women and 3,590 men) with 21,306 observations across the three waves: 7,198 at wave 4, 7,803 at wave 6, and 6,305 at wave 8, see chapter six, Figure 6.1. Dropped observations were more likely to be from individuals reporting being in poor health, the lowest two wealth quintiles and in paid work. Further details of sample selection can be found in chapter six, section 6.4. Nearly two thirds of the sample (63%) responded in all three survey waves, Table 7.1. Four percent of the sample had a gap in their response pattern, responding in waves 4 and 8, but not in wave 6.

Table 7.1: Wave response patterns, ELSA waves 4, 6 and 8

Wave pattern (4-6-8)	Frequency	%	Cumulative %
	8,089		
111	5,128	63.4	63.4
11.	1,784	22.0	85.4
.11	891	11.0	96.5
1.1	286	3.5	100.0

Data source: ELSA waves 4, 6 and 8; Author's own calculations

The main and sensitivity analyses detailed below were conducted using several different estimators and Table 7.2 summarises the numbers of cases for each analysis. Analysis of within- and between-variation is presented for sleep disturbance variables (Tables 7.3 and 7.4) and caregiving hours and relationship to care recipient (Table 7.5). These analyses provide evidence of sufficient change to run fixed effects models. Tables 7.4 and 7.5 also provide the percentage of sleep disturbance and caregiving variables by wave and gender. Chi-squared tests were used to assess differences in percentages and t tests assessed difference in mean sleep disturbance in Appendix Table D1; test results not shown but noted in the text. In longitudinal analyses, associations between caregiving hours and relationship and sleep disturbance were investigated using fixed effects models. Analyses were run first with fixed effects logit and then linear probability models (LPMs), as results from LPMs use the full sample and provide similar estimates to average marginal effect estimates from logit models, see Methodology section 5.4.4 (Breen, R. et al., 2018). Each analysis was stratified by gender. The results

for caregiving hours among women are presented in Table 7.6 and among men in Table 7.7. The results considering relationship to the care recipient among women are presented in Table 7.8 and among men in Table 7.9. Sensitivity analyses were run on the final model for each main analysis and results are presented in Appendix D, table numbers noted in the text. The first sensitivity analysis used a FE LPM, constrained to the same sample of cases as a logit model (Beck, 2020). A second sensitivity analysis measured sleep disturbance as a continuous rather than binary variable, checking the robustness of results to variable measurement level. The final sensitivity analysis used imputed data. Descriptive analyses were weighted using the relevant cross-sectional weight, while fixed effects models were carried out unweighted, and with cluster robust standard errors (Andres et al., 2013), see Methodology section 5.4.4.

Table 7.2: Number of cases and observations for analyses

	Women N: 4,499	Observations 11,840	Men N: 3,590	Observations 9,466
Fixed effects (FE) logit FE LPM (constrained)†	1,172	3,175	1,194	3,249
FE LPM FE linear †	4,499	11,840	3,590	9,466
FE LPM (imputed data) †	4,706	12,582	3,729	9,952

Notes: † sensitivity analyses, results included in Appendix D

7.3 DESCRIPTIVE STATISTICS

This section describes variation in study variables over waves 4, 6 and 8 as fixed effects models used in the longitudinal analyses require sufficient variation over time within individuals, while between individual variation is removed, reducing the influence of stable characteristics and prior circumstances.

7.3.1 Disturbed sleep

Table 7.3 includes transitions in sleep disturbance over the three waves for the full sample. Individuals ever reporting low sleep disturbance (sleep responses in the lowest two sex-specific tertiles) were more likely to continue to have low sleep disturbance, reported in 85% of responses. Responses of individuals ever reporting disturbed sleep (highest sex-specific tertile) were more likely to fluctuate, 54-58% of responses. This

high level of statistical dependence across waves is one justification for the use of panel data methods in this study (Andres et al., 2013).

Table 7.3: Sleep disturbance (highest tertile) stability across waves

Wave	Sleep disturbance	N	First order transition matrix: wave, wave+2		Higher order transition matrix: wave 4, wave	
			Low sleep disturbance	High sleep disturbance	Low sleep disturbance	High sleep disturbance
4	Low	5,208	85.7	14.3		
	High	1,704	41.8	58.2		
6	Low	4,525	84.7	15.3	85.7	14.3
	High	1,494	43.8	56.2	41.8	58.2
8	Low	4,108			84.1	15.9
	High	1,306			45.9	54.1

Data source: ELSA waves 4, 6 and 8; Author's own calculations. Tabulation of lags of two and four waves

Table 7.4 shows the frequency and percentage of men and women reporting sleep disturbance (highest sex-specific tertile) and within and between variation over the three waves. As noted in the Methodology section 5.3, the distribution of sleep disturbance was counter-intuitive among women and men given the distribution of the individual sleep problem variables used to derive the measure of sleep disturbance. Overall, women reported less sleep disturbance (22% in the full sample) than men (30%). The percentage of women reporting disturbed sleep varied little across the three waves of data, while the percentage among men rose over the three waves¹⁸. The second half of Table 7.4 describes variation in sleep disturbance. Most of the sample reported low sleep disturbance at least once (91% of women and 86% of men, between variation column). However, the same column also indicates that over a third of women (35%) and almost half of men (48%) reported sleep disturbance at least once. The within variation column highlights the amount of change within-individuals. For instance, among women who ever reported sleep disturbance, an average of 60% of their observations indicated sleep disturbance (StataCorp, 2017b). The equivalent figure for men was 64%. Overall, there was less within variation in sleep disturbance among women than men (79% of women's responses were stable compared to 75% of

¹⁸ $\chi^2_{(2)}$: 6.5, p=0.04, on unweighted pooled data

men). The lower proportion of women reporting sleep disturbance and lower within-person variation in sleep disturbance among women is reflected in the samples used to estimate coefficients in subsequent fixed effects logit models in sections 7.4 and 7.5. FE logit model coefficients are estimated using data only from those individuals who change their sleep disturbance responses over time (Andres et al., 2013). Similar statistics are provided for sleep measured continuously in Appendix Table D1.

7.3.2 Caregiving hours and relationship

Percentages and within and between variation of caregiving hours and relationship variables across the three waves of data are provided in Table 7.5, stratified by gender. The proportion of individuals caring for less than 20 hours per week and 20 or more hours per week changed little over the course of waves 4, 6 and 8 (5% and 4% respectively among women and 3% and 2% among men). However, the recipients of care altered over time. The percentage of women caring for a spouse increased over waves 4 to 8, while parent care and care to others decreased¹⁹, expected with sample ageing. Few men provided care to individuals other than a spouse or parent in waves 6 and 8. The second half of the table indicates that although the percentage of observations in each category of unpaid care was small when separated by hours of care or relationship of care, there was significant within-person change. For instance, among women, 3.5% of observations were for care of 20 or more hours per week. The between variation column indicates that 7.7% of women had ever provided care for 20 or more hours per week, these women reporting providing care of this level in just under half of all their observations (within variation). A similar pattern was found for all caregiving characteristics for women and men. Appendix Table D3 provides the frequency of transitions for caregiving characteristics in the data and confirms there were only 51 transitions to other care among men in the data. These statistics indicate sufficient variation in the data, except for other care for men. Descriptive statistics for covariates across the three waves of data are provided in Appendix Table D2. As described in section 6.4, the longitudinal sample differed from the baselines samples by having fewer individuals in the lowest two wealth quintiles or reporting poorer health.

¹⁹ $X^2_{(6)}$: 17.6, $p=0.007$, on unweighted pooled data

Table 7.4: Percentage and variation in disturbed sleep over waves 4-8 by gender

Variable:	Weighted percentage of sample			Variation across three waves (xttab) unweighted			Overall stability in sleep disturbance (average within variation)
	Wave 4 N=7,198	Wave 6 N=7,803	Wave 8 N=6,305	Overall person/ waves: 21,306 % (obs)	Between variation (ever reported)	Within variation (% stable for ever reported)	
<u>Women</u>							
Low	78.0	78.2	78.4	78.9 (9,342)	91.1	86.5	79.3
High (highest tertile)	22.0	21.8	21.6	21.1 (2,498)	34.9	60.7	
<u>Men</u>							
Low	70.3	69.3	67.7	69.7 (6,602)	85.5	81.2	75.0
High	29.7	30.7	32.3	30.3 (2,864)	47.8	64.0	

Data source: ELSA waves 4, 6 and 8. Author's own calculations. Weighted percentages weighted by relevant cross-sectional weight; abbreviations: obs, observations

Table 7.5: Percentage and variation in care hours and care relationship over waves 4-8, by gender

Variable	Weighted percentage of sample			Variation across three waves (xttab) unweighted			
	Wave 4 N=7,198	Wave 6 N=7,803	Wave 8 N=6,305	Overall person/ waves: 21,306 % (obs)	Between variation (ever provided) % (N)	Within variation (% stable for ever provided)	Overall stability in care variables (average within variation)
<u>Women</u>							
No care	91.3	91.8	91.7	91.9 (10,879)	98.6 (4,436)	93.1	85.6
<20 hours	4.9	4.2	4.8	4.6 (544)	10.6 (475)	43.3	
20+ hours	3.7	4.0	3.5	3.5 (417)	7.7 (346)	46.8	
Spouse	2.7	3.3	3.6	3.1 (363)	6.5 (292)	48.1	85.8
Parent	3.7	3.2	2.9	2.9 (347)	6.7 (300)	44.6	
Other	2.2	1.6	1.7	2.1 (251)	4.7 (213)	43.8	
<u>Men</u>							
No care	93.8	95.7	94.6	94.6 (8,956)	99.1 (3,557)	95.4	89.9
<20 hours	3.6	2.2	3.0	2.9 (271)	6.9 (249)	41.2	
20+ hours	2.6	2.1	2.4	2.5 (239)	5.3 (189)	48.9	
Spouse	2.8	2.6	2.5	3.0 (280)	6.0 (217)	49.2	90.1
Parent	2.2	1.2	2.1	1.5 (145)	3.6 (131)	42.5	
Other	1.2	0.5	0.1	0.9 (85)	2.2 (79)	41.3	

Data source: ELSA waves 4, 6 and 8. Author's own calculations. Weighted percentages weighted by relevant cross-sectional weight; abbreviations: obs, observations

7.4 LONGITUDINAL ASSOCIATIONS BETWEEN CAREGIVING HOURS AND DISTURBED SLEEP

This section reports on analyses addressing how caregiving hours (less than 20 hours per week, and 20 or more hours per week) are longitudinally associated with disturbed sleep, first among women and then among men. Results from logit fixed effect models (Models 1 to 3) and LPM FE models (Models 4 to 6) are presented for women in Table 7.6 and for men in Table 7.7. All coefficients represent the association with sleep disturbance of a change in status (categorical variables) or a one-unit increase (continuous variables), within any given individual in the sample. Model 1 estimated caregiving hours controlling for age, age-squared to identify non-linear age associations, wave, and marital status. Model 2 added socioeconomic characteristics, physical activity, physical health variables and self-rated health, and Model 3 added depressive symptoms. Results of sensitivity analyses are discussed in the text and reported in Appendix Tables D5 to D9. In all analyses, no associations were found between caregiving for less than 20 hours per week and disturbed sleep, irrespective of gender, therefore the following section focuses on care of 20 or more hours per week. Odds ratios (ORs) are reported for logit models and probability of disturbed sleep reported for LPMs, along with confidence intervals (CIs).

Table 7.6 provides the results of analysis of caregiving hours and disturbed sleep among women. It indicates a change in caregiving of 20 or more hours per week was associated with greater odds of disturbed sleep for a given woman, when models controlled for demographic variables (Model 1). The addition of socioeconomic characteristics, physical activity, physical health variables and self-rated health (Model 2) and depressive symptoms explained the increased odds (Model 3). Re-estimated using LPMs, the coefficients changed little across models and, a given woman with a change in caregiving of 20 or more hours a week had a 5% increased probability of sleep disturbance in Models 4 and 5. This was accounted for when depressive symptoms was added (Model 6). Of the other covariates included in the final logit and LPM models (Models 3 and 6), becoming a widow, and as expected, changes in moderate and severe pain, fair or poor self-rated health and high depressive symptoms were all associated with disturbed sleep. For instance, for a given woman, widowhood

increased the probability of sleep disturbance by 6% (CI 0.95: 0.02 – 0.11, Model 6). All coefficients reduced with the addition of depressive symptoms, which was associated with an 8% increased probability of sleep disturbance (CI 0.95: 0.05 – 0.11, Model 6). In the linear probability models only, moving into the lowest wealth quintile was associated with a 5% increase in the probability of sleep disturbance (CI 0.95: 0.00 – 0.09). Changes in age and other marital statuses, later waves of data, as well as changes in work and other wealth quintiles were not associated with sleep disturbance. Results did not differ in sensitivity analyses in Appendix D, except when sleep disturbance was measured continuously and using imputed data. When measured continuously, a given woman caregiving for 20 or more hours per week had a 0.11 point (3%) increase in sleep disturbance, scale range 1 to 4 (CI 0.95: 0.03 – 0.20, Table D5 Model 4). Using imputed data, the coefficient and confidence interval were the same as those estimated using complete cases, however, the coefficient was significant after adjustment for depressive symptoms, Table D9, CI 0.95: 0.05* (0.00 – 0.09).

Among the sample of men, Table 7.7, for any given man, change in caregiving of 20 or more hours per week was associated with higher odds of sleep disturbance, which increased with adjustment for depressive symptoms (OR 1.83, CI 0.95: 1.06 – 3.15, Model 3 Table 7.7). When re-estimated with LPMs, although the coefficients changed little across the three models, only the coefficient in Model 3 was significant, with the addition of depressive symptoms. In this model, for any given man, change in caregiving of 20 or more hours per week was associated with a seven percent higher probability of reporting disturbed sleep (CI 0.95: 0.00 – 0.14, Model 6, Table 7.7). The data was little different from the null hypothesis, however. Associations between health variables and disturbed sleep were similar to those found among women, while demographic associations were quite different. No association was found with widowhood, unlike among women but a change in being in the middle wealth quintile was associated with a 4% increase in sleep (CI 0.95: 0.00 – 0.08). Further, increasing age was associated with significantly lower probability of reporting disturbed sleep, while progressively higher probability of reporting disturbed sleep was found for each subsequent wave compared to wave 4. These associations present differing time trends. No such associations were found for women, and the association with later waves may indicate contextual change that influenced men's sleep more strongly than

women's sleep; while in any given man, older age reduced the probability of sleep disturbance. An example of contextual change is the 2008 recession, found to be associated with increased sleep problems in the US through greater financial problems, though this effect was found to be stronger among women than men (Bierman, 2021). In sensitivity analyses in Appendix D, an LPM constrained to the sample of men whose sleep response changed supported the results from the main logit and LPM FE (full sample) models: caregiving for 20 or more hours was associated with a 20% increase in sleep disturbance (CI 0.95: 0.03 – 0.37, Model 3, Table D6). When sleep disturbance was measured continuously (Model 4, Table D6) and when the LPM FE (full sample) was re-run using imputed data (Model 4, Table D7), the coefficient for 20 or more hours of care was not significant. These differences may indicate the effect of measurement of sleep disturbance, and the greater possibility of associations due to chance in the smaller complete case data (Sterne et al., 2009).

Overall, within person changes in caregiving for 20 hours per week in women and men were of a similar small magnitude, indicating a 5 - 7% increased probability of disturbed sleep. For women, the association was explained by changes in depressive symptoms in main analyses, while for men, the association was most consistent in men who reported a change in sleep disturbance. Further, the significance of caregiving coefficients was inconsistent across some main and sensitivity analyses for both genders. Results from these analyses were therefore sensitive to measurement level of the dependent variable and analytical model. Coefficients were similar, though differed in significance when estimated from LPMs run on complete case and imputed data. Taking this into account, equivocal and limited evidence was found in support of the hypothesis that longer caregiving hours are associated with sleep disturbance and limited evidence of differences by gender. Instead, consistent, and strong associations with changes in health were found, and differing associations with wealth, for both women and men, and in addition among women, the transition to widowhood and among men, age and possible broader contextual changes were also important.

Table 7.6: Fixed effects regression of disturbed sleep by caregiving hours, women, logit and linear probability models

	Logit models, odds ratios			Linear probability models, β coefficients		
	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, physical activity, physical health, SRH)	Model 3 (M2 + depressive symptoms)	Model 4 (as M1 but LPM)	Model 5 (as M2 but LPM)	Model 6 (as M3 but LPM)
Care<20 hrs/wk	0.94 (0.65 – 1.37)	0.95 (0.65 – 1.39)	0.95 (0.64 – 1.39)	-0.01 (-0.04 – 0.03)	-0.01 (-0.04 – 0.03)	-0.01 (-0.04 – 0.03)
20+ hours	1.65* (1.06 – 2.55)	1.55 (0.99 – 2.43)	1.47 (0.94 – 2.32)	0.05* (0.01 – 0.10)	0.05* (0.00 – 0.10)	0.05 (-0.00 – 0.09)
Age	0.89 (0.70 – 1.14)	0.97 (0.75 – 1.25)	0.98 (0.76 – 1.26)	-0.01(-0.03 – 0.01)	-0.00 (-0.03 – 0.02)	-0.00 (-0.02 – 0.02)
Age-squared	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	1.00 (1.00 – 1.00)	0.00 (-0.00 – 0.00)	-0.00 (-0.00 – 0.00)	-0.00 (-0.00 – 0.00)
Wave 6	1.33 (0.80 – 2.21)	1.14 (0.68 – 1.94)	1.16 (0.68 – 1.97)	0.03 (-0.02 – 0.07)	0.01 (-0.03 – 0.06)	0.01 (-0.03 – 0.06)
Wave 8	1.64 (0.61 – 4.41)	1.20 (0.43 – 3.35)	1.22 (0.43 – 3.42)	0.04 (-0.04 – 0.13)	0.02 (-0.07 – 0.11)	0.02 (-0.07 – 0.10)
Sep/div/single	1.13 (0.63 – 2.01)	1.25 (0.69 – 2.27)	1.19 (0.65 – 2.18)	0.01 (-0.05 – 0.08)	0.02 (-0.05 – 0.08)	0.02 (-0.05 – 0.08)
Widowed	1.84** (1.23 – 2.75)	1.90** (1.26 – 2.88)	1.74** (1.15 – 2.65)	0.07** (0.02 – 0.12)	0.07** (0.03 – 0.12)	0.06** (0.02 – 0.11)
In paid work		1.17 (0.93 – 1.47)	1.15 (0.91 – 1.44)		0.01 (-0.01 – 0.03)	0.01 (-0.01 – 0.03)
2 nd highest wealth		0.95 (0.69 – 1.31)	0.93 (0.67 – 1.29)		-0.00 (-0.03 – 0.02)	-0.00 (-0.03 – 0.02)
Middle		1.01 (0.70 – 1.44)	0.99 (0.69 – 1.42)		-0.00 (-0.03 – 0.03)	0.00 (-0.03 – 0.03)
2 nd lowest		0.84 (0.57 – 1.24)	0.83 (0.56 – 1.23)		-0.01 (-0.05 – 0.02)	-0.02 (-0.05 – 0.02)
Lowest		1.42 (0.92 – 2.18)	1.40 (0.91 – 2.15)		0.06* (0.00 – 0.09)	0.05* (0.00 – 0.09)
<Weekly activity		1.20 (1.00 – 1.45)	1.18 (0.98 – 1.43)		0.02 (-0.00 – 0.04)	0.02 (-0.00 – 0.04)
Non-limiting illness		1.03 (0.80 – 1.34)	1.02 (0.79 – 1.32)		0.00 (-0.02 – 0.02)	0.00 (-0.02 – 0.02)
Limiting illness		1.28 (0.99 – 1.64)	1.26 (0.97 – 1.62)		0.02 (-0.00 – 0.05)	0.02 (-0.00 – 0.05)
Mod/severe pain		1.43*** (1.17 – 1.75)	1.41** (1.16 – 1.73)		0.04*** (0.02 – 0.06)	0.04** (0.02 – 0.06)
Fair/poor SRH		1.58*** (1.26 – 1.99)	1.48** (1.18 – 1.86)		0.06*** (0.03 – 0.09)	0.05*** (0.03 – 0.08)
CES-D adapted 3+			1.73*** (1.40 – 2.14)			0.08*** (0.05 – 0.11)
R-squared			0.05 (Pseudo R2)			0.02 (within)

Notes: Models 1-3, N=1,172 women with 3,175 observations; Models 4-6, N=4,499 women with 11,840 observations; Reference categories are no caregiving; wave 4; married; retired/out of work; Highest quintile non-housing wealth; More than once weekly moderate or vigorous activity; No limiting illness; No or weak pain; Good or better self-rated health and less than 3 depressive symptoms (CES-D adapted, excluding sleep item); LPMs estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: English Longitudinal Study of Ageing, waves 4, 6 and 8. Author's own calculations.

Table 7.7: Fixed effects regression sleep disturbance by caregiving hours, men, logit and linear probability models

	Logit models, odds ratios			Linear probability models, β coefficients		
	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, health excl depressive symp)	Model 3 (M2 + depressive symptoms)	Model 4 (as M1 but LPM)	Model 5 (as M2 but LPM)	Model 6 (as M3 but LPM)
Care <20 hours	1.34 (0.84 - 2.14)	1.41 (0.87 - 2.28)	1.41 (0.87 - 2.29)	0.03 (-0.03 - 0.09)	0.03 (-0.03 - 0.09)	0.03 (-0.03 - 0.09)
Care 20+ hours	1.72* (1.02 - 2.91)	1.75* (1.03 - 2.98)	1.83* (1.06 - 3.15)	0.07 (0.00 - 0.14)	0.07 (-0.00 - 0.14)	0.07* (0.00 - 0.14)
Age	0.68** (0.54 - 0.87)	0.71** (0.55 - 0.92)	0.72* (0.56 - 0.93)	-0.05** (-0.08 - -0.02)	-0.04** (-0.08 - -0.01)	-0.04** (-0.07 - -0.01)
Age-squared	1.00* (1.00 - 1.00)	1.00* (1.00 - 1.00)	1.00 (1.00 - 1.00)	0.00 (-0.00 - 0.00)	0.00* (0.00 - 0.00)	0.00* (0.00 - 0.00)
Wave 6	2.17** (1.32 - 3.58)	2.00** (1.20 - 3.34)	2.00** (1.19 - 3.37)	0.10** (0.04 - 0.16)	0.09** (0.02 - 0.15)	0.09** (0.02 - 0.15)
Wave 8	5.48** (2.07 - 14.55)	4.62** (1.70 - 12.6)	4.58** (1.65 - 12.8)	0.21** (0.09 - 0.34)	0.19** (0.07 - 0.32)	0.19** (0.07 - 0.32)
Sep/div/single	1.30 (0.69 - 2.45)	1.15 (0.60 - 2.20)	1.22 (0.64 - 2.35)	0.03 (-0.04 - 0.11)	0.03 (-0.04 - 0.10)	0.03 (-0.04 - 0.10)
Widowed	1.70 (0.98 - 2.96)	1.86* (1.06 - 3.29)	1.73 (0.98 - 3.05)	0.07 (-0.01 - 0.15)	0.08 (-0.00 - 0.16)	0.07 (-0.01 - 0.15)
In paid work		0.96 (0.77 - 1.19)	0.96 (0.77 - 1.20)		-0.00 (-0.02 - 0.03)	-0.00 (-0.03 - 0.02)
2 nd highest wealth		1.11 (0.84 - 1.45)	1.11 (0.84 - 1.45)		0.01 (-0.02 - 0.04)	0.01 (-0.02 - 0.04)
Middle		1.32 (0.96 - 1.81)	1.31 (0.96 - 1.80)		0.04* (0.00 - 0.08)	0.04* (0.00 - 0.08)
2 nd lowest		1.12 (0.78 - 1.62)	1.12 (0.78 - 1.62)		0.02 (-0.02 - 0.06)	0.02 (-0.02 - 0.06)
Lowest		0.96 (0.63 - 1.46)	0.92 (0.63 - 1.44)		-0.01 (-0.06 - 0.04)	-0.01 (-0.07 - 0.04)
Activity		1.09 (0.90 - 1.32)	1.06 (0.87 - 1.28)		0.01 (-0.01 - 0.03)	0.01 (-0.02 - 0.03)
Non-limiting illness		1.07 (0.84 - 1.36)	1.06 (0.83 - 1.35)		0.01 (-0.02 - 0.04)	0.01 (-0.02 - 0.04)
Limiting illness		1.63*** (1.26 - 2.09)	1.57*** (1.22 - 2.02)		0.06*** (0.03 - 0.09)	0.06** (0.02 - 0.09)
Pain		1.56*** (1.26 - 1.93)	1.53*** (1.24 - 1.90)		0.07*** (0.03 - 0.09)	0.07*** (0.03 - 0.10)
Fair/poor SRH		1.40** (1.11 - 1.76)	1.34* (1.06 - 1.68)		0.06** (0.02 - 0.09)	0.05** (0.01 - 0.08)
CES-D adapted 3+			1.81*** (1.38 - 2.38)			0.10*** (0.06 - 0.14)
R-squared			0.05			0.02 (within)

Notes: Models 1 - 3, N=1,194 men with 3,249 observations; Models 4-6, N=3,590 men with 9,466 observations; Reference categories as Table 7.6; LPMs estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: English Longitudinal Study of Ageing, waves 4, 6 and 8. Author's own calculations.

7.5 LONGITUDINAL ASSOCIATIONS BETWEEN RELATIONSHIP OF CARE AND DISTURBED SLEEP

Results from analyses addressing how caregiver relationship to the care recipient is associated with sleep disturbance are reported in this section. Logit FE models (Models 1 to 3) and LPM FE models (Models 4 to 6) are displayed in Table 7.8 (women) and Table 7.9 (men). As for section 7.4, coefficients represent the association with sleep disturbance of a change in status (categorical variables) or a one-unit increase (continuous variables), within any given individual in the sample. Odds ratios (ORs) are reported for logit models and probability of disturbed sleep reported for LPMs, along with confidence intervals (CIs). Covariates were added in the same order as Table 7.6 and 7.7 in the previous section. The coefficients in Table 7.8 indicated no associations between any caregiving relationship and sleep disturbance among women. Women reporting a change in caregiving for more distant relatives or friends had lower but non-significant odds of reporting disturbed sleep. Any given spouse or parent caregiver had greater but non-significant odds of reporting disturbed sleep. The results were not substantively different when analysed with LPMs, Models 4-6. There was no difference in results from sensitivity analyses (including when re-run using imputed data) unless the dependent variable was measured continuously. When sleep disturbance was measured continuously, a given woman reporting a change in spouse care had a small increase in sleep disturbance, 0.10 or 3%, on a scale of 1 to 4 (CI 0.95: 0.00 – 0.20, Model 4, Table D7).

Among men, Table 7.9, a man reporting change in spouse care had higher odds of reporting disturbed sleep, in all logit FE models (fully adjusted OR 1.75, CI 0.95: 1.01 – 3.03, Model 3). However, in Models 4-6, using LPMs, although the direction of association was the same, spouse care coefficients were not significant, indicating raised odds of sleep disturbance among men with a change in sleep disturbance, though not among the full sample of men. No association was found with caregiving for a more distant relative or friend, or a parent, and disturbed sleep in any of the models. In sensitivity analyses in Appendix D, consistent with results from logit FE models, any given man reporting a change in spouse care had a 18% greater probability of sleep disturbance (CI 0.95: 0.01 – 0.36, Table D8, Model 3), modelled using an LPM

constrained to cases reporting change in sleep response. Linear FE models with the continuous sleep measure indicated a 0.11-point, 3%, increase in sleep disturbance on the scale of 1 to 4 (CI 0.95: 0.00 – 0.21, Table D8, Model 4). Results from imputed data were consistent with complete case LPMs, finding no association with spouse care, Table D9.

In summary, results from analyses of caregiving relationship and sleep disturbance indicated limited evidence of an association between providing care for a spouse and sleep disturbance, and none with other relationships with the care recipient. Among women, a within-person change in spouse care was associated with a small (3%) increase in sleep disturbance when measured continuously but not in any main models or sensitivity models using the dichotomous dependent variable. Among men, associations were found with spouse care in models using data from men whose sleep response changed and with sleep measured continuously. For instance, for any given man, spouse care was associated with a 19% increased probability of disturbed sleep in constrained LPMs. Although results are inconsistent, the evidence is suggestive of a gender difference in spouse care, with a small increased probability of sleep disturbance in men but not women.

Table 7.8: Fixed effects regression of sleep disturbance by caregiving relationship, women, logit and linear probability models

	Logit models, odds ratios			Linear Probability Models, β coefficients		
	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, health excl depressive symp)	Model 3 (M2 + depressive symptoms)	Model 4 (as M1 but LPM)	Model 5 (as M2 but LPM)	Model 6 (as M3 but LPM)
Other care	0.84 (0.48 – 1.46)	0.84 (0.47 – 1.47)	0.84 (0.47 – 1.49)	-0.02 (-0.07 – 0.04)	-0.02 (-0.07 – 0.03)	-0.02 (-0.07 – 0.04)
Parent care	1.42 (0.87 – 2.32)	1.41 (0.85 – 2.34)	1.37 (0.82 – 2.27)	0.03 (-0.01 – 0.08)	0.03 (-0.01 – 0.08)	0.03 (-0.02 – 0.08)
Spouse care	1.31 (0.80 – 2.13)	1.24 (0.75 – 2.03)	1.20 (0.73 – 1.97)	0.03 (-0.02 – 0.08)	0.03 (-0.02 – 0.08)	0.02 (-0.03 – 0.08)

Notes: Models 1-3, N=1,172 women with 3,175 observations; Models 4-6, N=4,499 women with 11,840 observations; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); LPMs estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: English Longitudinal Study of Ageing, waves 4, 6 and 8. Author's own calculations.

Table 7.9: Fixed effects regression of sleep disturbance by caregiving relationship, men, logit and linear probability models

	Logit models, odds ratios			Linear Probability Models, β coefficients		
	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, health excl depressive symp)	Model 3 (M2 + depressive symptoms)	Model 4 (as M1 but LPM)	Model 5 (as M2 but LPM)	Model 6 (as M3 but LPM)
Other care	1.09 (0.51 – 2.35)	1.21 (0.55 – 2.68)	1.27 (0.57 – 2.84)	0.00 (-0.11 – 0.12)	0.01 (-0.11 – 0.12)	0.01 (-0.11 – 0.12)
Parent care	1.56 (0.83 – 2.93)	1.50 (0.79 – 2.84)	1.59 (0.83 – 3.01)	0.05 (-0.03 – 0.14)	0.05 (-0.03 – 0.14)	0.06 (-0.03 – 0.14)
Spouse care	1.69 (1.00 – 2.87)	1.78* (1.04 – 3.05)	1.75* (1.01 – 3.03)	0.06 (-0.00 – 0.12)	0.06 (-0.00 – 0.12)	0.06 (-0.00 – 0.12)

Notes: Models 1-3, N=1,194 men with 3,249 observations; Models 4-6, N=3,590 men with 9,466 observations; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); LPMs estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001; Data source: English Longitudinal Study of Ageing, waves 4, 6 and 8. Author's own calculations.

7.6. CONCLUSION

This chapter investigated longitudinal associations between caregiving hours and relationship to the care recipient and sleep disturbance. Associations were found with some caregiving characteristics that might be experienced or perceived as stressful and counter to expectations, gender differences were slight, or disturbance found among men rather than women caregivers. In the main models, within-person changes in longer hours of care were associated with sleep disturbance among men, while the same association was explained by depressive symptoms among women. Changes in spouse care were associated with sleep disturbance only among men. However, associations were weak and varied by model. In detail, results indicated a woman or man caregiving for 20 hours or more per week had a small (5-7%) increased probability of sleep disturbance. Among women, the association was accounted for by changes in depressive symptoms in FE logit and LPM models, though remained when analysing imputed data. Among men, the association was only significant when a FE LPM model was adjusted for depressive symptoms and the association did not hold when sleep disturbance was measured continuously, or when the FE LPM model was re-run on imputed data (though the coefficient and confidence interval were similar). For both genders, providing less than 20 hours of care per week was not associated with sleep disturbance. The second part of the chapter analysed relationship to the care recipient and sleep disturbance. Of the relationships investigated, spouse care was associated with sleep disturbance in all FE models among men, except in the FE LPMs where the coefficient showed the same trend but did not reach the conventional level of significance. In contrast to hypothesized associations, only in linear FE models was there evidence of a small increase in sleep disturbance for a woman when providing spouse care. No associations were found with either parent care or care to others for either gender. Changes in a female or male respondent's health, particularly depressive symptoms, were strongly associated with sleep disturbance, expected from the epidemiological literature on sleep. Becoming a widow, among women, and responding at later waves, among men, were other variables that increased sleep disturbance.

The results, while inconsistent, provide some support for previous studies finding associations between longer hours of care per week and sleep disturbance (Arber &

Meadows, 2011b; Maun et al., 2020; Sacco et al., 2018). Prior studies have also found higher sleep disturbance among spouse caregivers than non-caregivers, though only among individuals reporting high depressive symptoms (Kochar et al., 2007). A handful of studies have considered gender differences in caregiver sleep. Limited differences found in the analysis of caregiving hours is consistent with analysis of European individuals aged 50 and over (van de Straat et al., 2021). Associations found among men but not women who reported change in spouse care are more consistent with results from studies of a younger sample of working age adults (Sacco et al., 2018) and a study of mid-life German adults (Hajek & Koenig, 2022). That depressive symptoms was strongly associated with sleep disturbance is consistent with previous longitudinal studies adjusting for mental health (Rowe et al., 2008; Sacco et al., 2018; von Kaenel et al., 2012; von Kaenel et al., 2014). All but Sacco and colleagues found depressive symptoms, rather than caregiving, were associated with subjective sleep disturbance. However, the studies differed significantly, addressing all working adults and spouses of people with dementia or Alzheimer's disease. Previous longitudinal studies of mid- and later life adults did not adjust for depressive symptoms.

Interpreting these results, although women and men take on similar hours and tasks caring for an ill spouse (Langner & Furstenberg, 2020), becoming a caregiver may be unexpected. For men, this may involve taking on a role and tasks not encountered earlier in the life course (Calasanti & King, 2007; Pearlin & Aneshensel, 1994). Adapting to these changes may be perceived as stressful and could lead to sleep disturbance among men. Models were adjusted with several different measures of health, however, there may be residual confounding by health among men, as in chapter six, Table 6.4, men caregiving for a spouse and for longer hours per week had significantly poorer health than non-caregivers. Among women, that care of 20 or more hours was no longer significant with addition of depressive symptoms may indicate sleep disturbance arising concurrently with, or as a symptom of, depressive symptoms (Hiel et al., 2015). Mood has been found to mediate associations between dementia care and poor sleep quality (Brummett et al., 2006). However, the analyses in the thesis did not assess whether sleep disturbance was found only among depressed women caregivers as found by Kochar and colleagues (2007). With regards to relationship to the care

recipient, no association with sleep disturbance was found with spouse care among women, but a consistent association was found on becoming a widow, hardly affected by the addition of depressive symptoms. Although women spouse caregivers have been found to have greater burden and poorer mental health than non-caregivers, there may be benefits from providing care which support sleep among women spouse caregivers. Pristavec (2019) used latent class analysis to estimate profiles of caregivers from reported benefits and burden. “Intensive caregivers” reported high burden but also moderate benefits that may be important for women caregiving for a spouse and allow them to maintain their sleep (Pristavec, 2019). That a woman becoming widowed had a greater probability of sleep disturbance suggests that the loss of a spouse, rather than the provision of care to a spouse, may be more likely to affect sleep. Widowhood can usher in stressors across a wide range of life domains that may have implications for health (Umberson & Thomeer, 2020). Further, patterns of disturbed sleep developed in the last months of a partner’s life can continue well into widowhood (Arber & Venn, 2011; Walker et al., 2012). Increased sleep disturbances have been associated with bereavement and may continue following interventions for grief (Lancel, Stroebe, & Eisma, 2020). In relation to parent and care to others, no association with parent care may be an indication of the buffering effects of holding multiple roles in mid-life, studies indicating parent care can have neutral or beneficial effects on health (Barnett, 2015; Bom & Stöckel, 2021; Glaser et al., 2005; van de Straat et al., 2021). In addition, although sleep disturbance was assumed to be related to caregiving stress, it may be more likely in situations of night-time care, more likely to be undertaken by a spouse.

Together the results in this chapter provide limited evidence of associations between longer caregiving hours (among women and men) and spouse care (among men) and small increases in sleep disturbance. Stronger associations were found with changes in individual health among both genders, widowhood among women and reducing sleep disturbance with older age among men. The next chapter considers whether the stage within a caregiving trajectory and the duration of care are important to associations with sleep disturbance, measuring care provision as care of 20 hours or more per week.

Chapter eight - Caregiving transitions, duration of care and sleep disturbance

8.1 INTRODUCTION

This chapter examines whether associations between caregiving for 20 hours per week and sleep disturbance vary at different points of transition and stability, as well as by duration. The previous chapter found evidence of small increases in sleep disturbance associated with within-person change in care provision of this intensity, among both women and men. However, associations may differ over time, when starting to provide care, when ceasing care, and during periods of stability, when continuing to care over several years. Caregiving circumstances and stressors can fluctuate over time which may have consequences for health and wellbeing (Pearlin & Aneshensel, 1994). For instance, different associations have been found with transitions into and out of care provision and periods of stability in analysis of depressive symptoms, quality of life and life satisfaction (Rafnsson et al., 2017). The aim of the chapter is to investigate how transitions and stability in caregiving, as well as the duration of caregiving, are associated with sleep disturbance. Panel models analysed within-person changes in caregiving and the probability of sleep disturbance at different points in a care episode. As up to three waves of sleep data were used, fixed effects models did not provide “instantaneous” change estimates for sleep disturbance that are produced with just two waves of data (Andres et al., 2013). For this reason, pooled multinomial logistic regression models regressed change in sleep disturbance on caregiving transitions to assess how sleep may change following a change in care. Finally, associations between care duration, of one wave or two or more waves, and sleep disturbance were examined using random effects models. The research questions addressed in this chapter are:

Research question 2: What are the longitudinal relationships between caregiving transitions (starting and ceasing caregiving of 20 hours or more per week) and periods of stability (continued caregiving) and sleep disturbance among women and men?

Research question 3: How do these relationships change when change in sleep disturbance is measured?

Research question 4: How is duration of caregiving (over one wave, or two or more waves) associated with sleep disturbance among women and men?

Section 8.2 of the chapter outlines the statistical approach and samples used in analyses after incorporating data from waves 3, 5 and 7 required to compute caregiving transitions/stability across consecutive waves, and care duration. Descriptive statistics for within and between variation in caregiving variables are presented in section 8.3 as well as the distribution of the care duration variable. Section 8.4 reports longitudinal analyses for analyses of caregiving transitions and sleep disturbance, and then for change in sleep disturbance. Tables for these analyses are provided at the end of section 8.5. Results of investigations into caregiving duration and sleep disturbance are presented in section 8.5. Section 8.6 summarises and interprets the results from all sections and provides concluding remarks.

8.2 SAMPLES AND ANALYTIC APPROACH

The sample for analysis of caregiving transitions and sleep disturbance, and for care duration and sleep disturbance included 6,771 individuals, 3,768 women and 3,003 men, with 17,047 observations, Table 8.1. This sample was smaller than for analyses in chapter 7, dropping individuals with less than two complete waves of the caregiving transitions variable, which required valid caregiving responses in two of consecutive waves 3 and 4, waves 5 and 6 and waves 7 and 8. The sample was older, had a smaller proportion of individuals in the lowest two wealth quintiles, fewer widows and fewer individuals reporting poor self-rated health and high depressive symptoms compared to the dropped cases. Change in sleep disturbance was analysed for care transitions among women only as the number of observations was low among men, particularly for continued care, see section 8.3. A maximum of two change in sleep measurements were possible with three waves of sleep data, the sample was therefore smaller than for the other analyses, a total of 6,422 observations from the sample of 3,768 women. Full details of the sample selection process are provided in Descriptive statistics section 6.4.

Variable coding is described in Methodology section 5.3. All caregiving variables referred to caregiving of 20 or more hours per week. In brief, the transitions/stability variable categories included no caregiving in either wave, starting caregiving, providing care in both waves and ceasing caregiving. Care duration was the sum of reported caregiving in available waves from waves 3 to 8 and categorised no care, care of one wave or care of two or more waves. Change in sleep disturbance measured combinations of presence or absence of sleep disturbance in the consecutive waves in which sleep was measured (waves 4 and 6, waves 6 and 8 and for 96 women without wave 6 data, waves 4 and 8²⁰, noted t-2 and t). Change in sleep disturbance included stable low disturbance, improved sleep (sleep disturbance t-2, none in t); sleep disturbance onset (none at t-2, sleep disturbance at t) and stable sleep disturbance (sleep disturbance at t-2 and t). The main and sensitivity analyses conducted used several different model types and Table 8.1 summarises the cases and observations for each analysis.

Table 8.1 Number of cases and observations for analyses

	Care transitions and sleep disturbance	Care transitions and change in sleep disturbance	Care duration (time-invariant) and sleep disturbance
Analysis	FE and RE LPMs	Multinomial logistic regression	RE LPMs
Women N (obs)	3,768 (9,476)	3,768 (6,422) †	3,768 (9,476)
Men N (obs)	3,003 (7,571)	N/A	3,003 (7,571)
Imputed data ††			
Women N (obs)	4,706 (12,582)	N/A	N/A
Men N (obs)	3,729 (9,952)		

† Only two waves of change in sleep could be coded from three waves of sleep

†† sensitivity analysis, results in Appendix E

Abbreviations: obs, observations

Descriptive statistics provide information on variation in caregiving transitions and stability for women and men in the longitudinal sample, Table 8.2 and Table 8.3. Tables 8.4 and 8.5 present the distribution of care duration. Investigations of associations between care transitions/stability and sleep disturbance were carried out with fixed

²⁰ Results did not differ in sensitivity analysis without these women (not shown).

and random effects linear probability models, in section 8.4. Although a Hausman test carried out on the coefficients from the final model indicated differing within and between processes for socioeconomic and health variables (see Appendix E1²¹ where both models are presented). However, random effects LPM coefficients differed little from those estimated by FE LPMs and the discussion focuses on the latter. Analysis of associations between caregiving transitions and changes in sleep disturbance were carried out using pooled multinomial logistic regression as change in sleep was a four-category nominal variable, following previous research (van de Straat et al., 2021). RE LPMs were used to investigate associations between care duration and sleep disturbance as care duration was time-invariant. Sensitivity analyses were conducted as noted in each section and results included in the Appendix E. Descriptive analyses were weighted using the relevant cross-sectional weight, while random and fixed effects models and pooled multinomial logistic regressions were carried out unweighted, and with robust standard errors (Andres et al., 2013), see Methodology section 5.4.4.

8.3 DESCRIPTIVE STATISTICS

In this section, the frequency and percentages across waves of caregiving transitions and continuous care are presented in Table 8.2. The table also summarises within and between variation, an indicator of sufficient change for subsequent panel models. Frequency of transitions are provided in Table 8.3, indicating categories with few transitions. The distribution of care duration in years by gender is presented in Table 8.4 and the derived three category variable in Table 8.5.

Table 8.2 summarises the percentage of caregiving transitions and stability (continuous care) in the sample, and the amount of within and between variation across waves by gender. The percentage of observations of individuals starting to provide care of 20 hours per week, continuing care over two waves or ceasing such care was less than 2.5% of all observations in a wave for both women and men. This was to be expected as the overall prevalence of caregiving of 20 or more hours in the cross-sectional samples

²¹ Hausman test statistic: $X^2_{(19)} = 128.6$, $p < 0.001$, Models 3 and 6, see Appendix Table E1. Hausman test was conducted on FE and RE models without robust standard errors (Cameron and Trivedi, 2009).

was approximately 3% and individuals had a maximum of three measurements of caregiving transition. For both women and men, continued provision of care across two waves was least likely to be reported, about 1% of observations in a wave, as most caregivers provided care for only one wave, see below. Although the percentage of caregiving transitions in the sample was low, within-variation was available to estimate coefficients using fixed effects models, as shown on the right side of the table. For instance, 5% of women ever reported starting to provide care (between variation) and starting care accounted for just over 40% of their observations (within variation). Table 8.3 provides the frequency of transitions in the data. The number of transitions was low for men across all categories, particularly for men providing continuous care where only 33 transitions were available. The results of analyses, particularly those for men, may be open to type II error as a result. Van den Broek and Grundy (2018b) noted low levels of transition as a limitation in their study of parent care (64 transitions in a sample containing 1,485 observations), see Conclusions section 10.4 for further discussion.

Table 8.4 summarises data on care duration of 20 or more hours per week for men and women who ever provided such care. Over 60% of caregivers reported providing care of 20 hours per week for only one wave (approximately two years). 21% of women and 18% of men reported providing care for two waves, and the remaining individuals provided care for longer periods. This is comparable to the average duration of spouse care in analysis of German panel data, found to be 2.7 years (standard deviation 2.6) (Gerlich & Wolbring, 2021); though these are not analogous measures of care provision. To ensure sufficient individuals for analysis, the care duration variable was divided into caregiving for one wave (two years) or two or more waves (four or more years), Table 8.5. Women provided more care of both one (8%) and two or more waves (4%) than men (5% and 3% respectively).

Table 8.2 Percentages and variation in care transitions, women and men

	Weighted percentages			Variation across three waves (unweighted)			
	Wave 4 (transition w3 to w4)	Wave 6 (transition w5 to w6)	Wave 8 (transition w7 to w8)	Overall person/ waves % (obs)	Between variation (ever been) % (N)	Within variation (% stable for ever been)	Overall stability (average within variation)
Women (N=3,678)							
No care/care<20hrs	93.9	94.6	94.5	94.4 (8,949)	98.6 (3,714)	95.7	89.6
Started care 20+hrs	2.1	2.0	2.2	2.1 (203)	5.1 (192)	43.7	
Continued care 20+hrs	1.4	1.2	1.3	1.2 (111)	2.6 (97)	46.9	
Ceased care 20+hrs	2.6	2.3	2.0	2.2 (213)	5.4 (202)	42.0	
Men (N=3,003)							
No care/care<20hrs	96.0	95.2	95.6	95.6 (7,242)	98.5 (2,959)	96.9	92.3
Started care 20+hrs	1.6	1.6	2.1	1.7 (129)	3.9 (118)	44.8	
Continued care 20+hrs	1.3	1.0	0.6	0.9 (72)	1.9 (57)	51.5	
Ceased care 20+hrs	1.0	2.2	1.8	1.7 (128)	3.9 (118)	44.3	

Data source: English Longitudinal Study of Ageing, waves 3, 4, 5, 6, 7 and 8. Author's own calculations. Weighted by relevant cross-sectional weight. Abbreviations: obs, observation

Table 8.3 Frequency of transitions – caregiving transitions

	Women	Men
No care/care<20hrs	299	116
Started care 20+hrs	167	60
Continued care 20+hrs	91	33
Ceased care 20+hrs	187	61

Notes: transitions calculated manually, using lag of two waves. Transitions counted for movement between waves of 1 to 0 (for example, starting to provide care to no care)

Table 8.4 Distribution of duration of care of 20 or more hours per week by gender

	N:	Percentages, total number of waves of care						Mean waves	Mean years†
		1	2	3	4	5	6		
Women	443	65.5	20.5	8.4	4.1	1.6	0	1.6	3.2
Men	257	63.8	17.5	9.7	6.2	2.0	0.8	1.7	3.4

Data source: ELSA waves 3 to 8; sum of the number of waves of care reported across waves 3 to 8; unweighted; † is an approximation, mean waves x 2 years (ELSA surveys carried out every 2 years)

Table 8.5 Derived variable for duration of care, 20 or more hours per week

	No care/ care<20hrs % (Obs)	1 wave % (Obs)	2+ waves % (Obs)
Women	88.3 (8,364)	7.6 (724)	4.1 (388)
Men	91.6 (6,933)	5.4 (408)	3.0 (230)

Data source: ELSA waves 3 to 8; N: women 3,768, men 3,003; unweighted; abbreviation: obs, observation

8.4. ASSOCIATIONS BETWEEN CAREGIVING TRANSITIONS AND SLEEP DISTURBANCE, AND CHANGE IN SLEEP DISTURBANCE

This section addresses research questions 2 and 3: what are the longitudinal relationships between caregiving transitions (starting and ceasing caregiving) and periods of stability (continued caregiving) and sleep disturbance among women and men? (Question 2); and what changes are seen when change in sleep disturbance is measured? (Question 3). Results from random effects LPMs (Models 1 to 3) and fixed effects models (Models 4 to 6) are presented for women in Table 8.6 and for men in Table 8.7. Change in sleep disturbance, using pooled multinomial logistic regression, was analysed for women only (Table 8.8), as observations for men were low in the main sample and would be further reduced by losing a wave of data. Tables are provided at the end of section 8.5. After carrying out analyses, sensitivity analyses were run, reported in Appendix E and results discussed in the text. Results are described below first for women and then men. As for chapter seven, coefficients represent the

probability of sleep disturbance of a change in status within any given individual in the sample. Covariates were included in the models in the same order as chapter seven.

Among women, counter to hypothesised relationships, coefficients for within-person change of starting to provide care and continuing to provide care were positive but not significant in both random and fixed effects models (Table 8.6). However, cessation of care was associated with sleep disturbance in the initial model adjusted for demographic characteristics. The coefficient only slightly decreased with adjustment for health factors in the second model. Following adjustment for depressive symptoms in the final model, a given woman ceasing care provision had a 7% increased probability of sleep disturbance in the fixed and random effects LPMs (Model 6, CI 0.95: 0.01 – 0.13). Other coefficients differed little between RE and FE models, though associations between health covariates and sleep disturbance were stronger in RE than FE models as might be expected as coefficients include both within and between variation. Of interest, in RE models, widows had a higher probability of sleep disturbance in Model 1, but this association was explained by wealth, where being in the lowest wealth quintile was associated with sleep disturbance (β 0.07, CI 0.95: 0.04 – 0.10 in Model 2 and 3). In FE LPMs in the previous chapter, widowhood was associated with sleep disturbance, see Table 7.6. In FE LPMs in Table 8.6, the coefficient for becoming a widow was positive but not significant in Models 1 and 3 and significant but very close to the null hypothesis in Model 2. This suggests widows reporting sleep disturbance may have provided care prior to bereavement, widowhood closely associated with ceasing care, which was associated with sleep disturbance. Sensitivity analysis was carried out controlling for respondent number of ADL difficulties and total diagnosed conditions, to rule out possible deteriorating caregiver health as an explanation for the association found between ceasing care and sleep disturbance (de Zwart et al., 2017). No difference was found in results, see Appendix Table E2. Similar associations were found in sensitivity analysis measuring sleep disturbance as a continuous variable, though continuous care provision was also significant in random effects but not fixed effects models, Appendix Table E3. When the final model of each main analysis was run on imputed data, Table E6, no associations were found with ceasing care however, and instead an association was found with starting to provide care using a fixed effects LPM

(β 0.05, CI 0.95: 0.00 – 0.11). Further, although ceasing care provision was not associated with sleep disturbance modelled with imputed data, a woman becoming a widow had a small increased probability of sleep disturbance, as found in chapter seven (β 0.05, CI 0.95: 0.01 – 0.10).

When analysing change in sleep disturbance among women, Table 8.7, results from pooled multinomial logistic regression indicated no associations between starting to provide care or continuing to provide care and any change in sleep disturbance. However, ceasing caregiving was also associated with a greater risk of stable sleep disturbance (at the wave prior to and after cessation of care), relative risk ratio: RRR: 2.35 (CI 0.95: 1.40 – 3.95); as well as sleep disturbance onset (no sleep disturbance prior to ceasing care but reported sleep disturbance in the wave following care cessation), RRR: 1.72 (CI 0.95: 1.01 – 2.94). Sensitivity analysis carried out using sleep disturbance measured continuously as the dependent variable, Table E4, found no associations including with ceased care. This sensitivity analysis was run as a first difference model, modelling change within individuals. It suggests the associations between ceasing care and sleep disturbance may be capturing sleep disturbance already present.

Turning to the sample of men, few associations were found between caregiving transitions and sleep disturbance, Table 8.8. In random effect models, starting to provide care of 20 or more hours per week was significantly associated with sleep disturbance. However, the association was explained once socioeconomic status and health variables were added in Model 2. No caregiving coefficients were significant in fixed effects models; a result also found when the final model was re-run on the imputed data, Appendix Table E6. Change models were not run for men as number of transitions would be reduced further with a loss of one wave of data. In the previous chapter, a within-person change in caregiving for 20 hours per week was associated with a small increased probability of sleep disturbance. The low frequency of transitions among men in the data may have made it less likely an association would be detected in the analysis in this chapter as a result.

8.5 ASSOCIATIONS BETWEEN DURATION OF CARE AND SLEEP DISTURBANCE

Random effects LPMs were used to investigate associations between care duration and sleep disturbance, as care duration was coded as a time-invariant variable, the sum of all instances of care of 20 hours per week for each individual. As noted in Methodology section 5.4, the same analysis was conducted on a sample excluding those who provided care at baseline, following other studies (Lacey et al., 2018). However, the number of individuals providing care for two or more waves was small in the latter sample, particularly for men²², results were similar to those from the full sample and are therefore not presented. Results from the full sample are presented in Table 8.9 Model 1, for women and Model 2, for men. Among women, caregiving for two or more waves increased the probability of sleep disturbance compared to non-caregivers by 7% (CI 0.95: 0.02 – 0.13). Caregiving for one wave only was not associated with sleep disturbance. Among men, no differences in sleep disturbance were found by care duration. Similar results were found when sleep disturbance was measured continuously, Appendix Table E7. The demographic and socioeconomic characteristics of those providing care of 20 hours or more for one wave or two or more waves were compared to those not providing care, see Appendix E8. For women, providing care of one wave was associated with being married, while men had a higher relative risk if out of paid work. Relative risk of providing care for two or more waves was higher among married women and men and those who were not in paid work. Both women and men in the lowest wealth quintile had a higher relative risk of providing care for two or more waves compared to not providing care. In addition, women's relative risk increased as their socioeconomic status decreased, measured by wealth (coefficients showed a similar pattern among men but were not significant). Socioeconomic status, including early life socioeconomic status has been associated with sleep problems in later life (Friedman et al., 2007; van de Straat et al., 2020). As change could not be assessed before and after the onset of care duration, it is possible caregivers providing two or more waves of care were more likely to report disturbed sleep prior to commencing care.

²² Excluding those providing care at their baseline wave, 57 men and 101 women provided care for two or more waves.

Table 8.6 Random effects and fixed effects LPMs of sleep disturbance by caregiving transition in care of 20 hours per week, women

	RE LPMs, β coefficients			FE LPMs, β coefficients		
	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, health excl depressive symp)	Model 3 (M2 + depressive symptoms)	Model 4 (covariates as M1)	Model 5 (covariates as M2)	Model 6 (covariates as M3)
Binary sleep disturbance						
Start 20+hr care	0.03 (-0.02 - 0.08)	0.03 (-0.02 - 0.08)	0.02 (-0.03 - 0.07)	0.02 (-0.04 - 0.08)	0.02 (-0.04 - 0.08)	0.01 (-0.05 - 0.07)
Continued care	0.05 (-0.03 - 0.13)	0.04 (-0.04 - 0.12)	0.03 (-0.05 - 0.11)	0.03 (-0.06 - 0.13)	0.03 (-0.07 - 0.12)	0.02 (-0.08 - 0.11)
Cease 20+hr care	0.09** (0.04 - 0.15)	0.08** (0.03 - 0.14)	0.07* (0.01 - 0.13)	0.08* (0.02 - 0.14)	0.08* (0.01 - 0.14)	0.07* (0.01 - 0.13)
Age	-0.01* (-0.02 - 0.00)	-0.01* (-0.02 - 0.00)	-0.01* (-0.02 - -0.00)	-0.03* (-0.06 - -0.00)	-0.02 (-0.05 - 0.01)	-0.02 (-0.04 - 0.01)
Age-squared	0.00* (0.00 - 0.00)	0.00 (0.00 - 0.00)	0.00 (0.00 - 0.00)	0.00 (-0.00 - 0.00)	0.00 (-0.00 - 0.00)	0.00 (-0.00 - 0.00)
Wave 6	0.02* (0.00 - 0.03)	0.01 (0.00 - 0.03)	0.02* (0.00 - 0.03)	0.06* (0.01 - 0.11)	0.05 (-0.00 - 0.09)	0.05 (-0.00 - 0.10)
Wave 8	0.02 (-0.00 - 0.04)	0.01 (-0.00 - 0.04)	0.02 (-0.00 - 0.03)	0.10* (0.00 - 0.20)	0.07 (-0.02 - 0.17)	0.07 (-0.03 - 0.17)
Sep/div/single	0.03* (0.00 - 0.06)	-0.00 (0.03 - 0.02)	-0.01 (0.04 - 0.01)	0.03 (-0.05 - 0.10)	0.03 (-0.04 - 0.11)	0.03 (-0.04 - 0.11)
Widowed	0.04** (0.01 - 0.07)	0.02 (-0.01 - 0.04)	0.00 (-0.02 - 0.03)	0.05 (-0.00 - 0.10)	0.05* (0.00 - 0.11)	0.04 (-0.01 - 0.10)
In paid work		-0.01 (-0.03 - 0.01)	-0.00 (-0.02 - 0.02)		0.01 (-0.02 - 0.03)	0.01 (-0.02 - 0.03)
2 nd highest wealth		0.01 (-0.01 - 0.04)	0.01 (-0.01 - 0.04)		0.01 (-0.02 - 0.04)	0.01 (-0.02 - 0.04)
Middle		0.01 (-0.01 - 0.04)	0.01 (-0.01 - 0.04)		-0.01 (-0.04 - 0.02)	-0.01 (-0.04 - 0.02)
2 nd lowest		0.02 (-0.01 - 0.05)	0.01 (-0.01 - 0.04)		-0.01 (-0.05 - 0.03)	-0.01 (-0.05 - 0.03)
Lowest		0.07*** (0.04 - 0.10)	0.07*** (0.04 - 0.10)		0.04 (-0.01 - 0.09)	0.04 (-0.01 - 0.09)
<Weekly activity		0.02* (0.01 - 0.04)	0.02 (-0.00 - 0.03)		0.01 (-0.01 - 0.03)	0.01 (-0.01 - 0.03)
Non-limiting illness		0.02* (0.00 - 0.04)	0.02* (0.00 - 0.04)		0.01 (-0.01 - 0.04)	0.01 (-0.01 - 0.03)

Limiting illness	0.04*** (0.03 - 0.07)	0.04*** (0.02 - 0.06)	0.03* (0.00 - 0.06)	0.03 (-0.00 - 0.05)
Mod/severe pain	0.08*** (0.06 - 0.10)	0.07*** (0.05 - 0.09)	0.03* (0.00 - 0.05)	0.03* (0.00 - 0.05)
Fair/poor SRH	0.11*** (0.08 - 0.13)	0.08*** (0.06 - 0.11)	0.06*** (0.03 - 0.09)	0.05*** (0.02 - 0.08)
CES-D adapted 3+		0.14*** (0.12 - 0.17)		0.08*** (0.05 - 0.11)

Notes: 3,768 women with 9,476 observations; Reference categories are no caregiving; wave 4; married; retired/out of work; highest quintile non-housing wealth; more than once weekly moderate or vigorous activity; no limiting illness; no or weak pain; good or better self-rated health and less than 3 depressive symptoms (CES-D adapted, excluding sleep item); * p<0.05, ** p<0.01, *** p<0.001; Estimated with robust standard errors; unweighted. Data source: English Longitudinal Study of Ageing, waves 3, 4, 5, 6, 7 and 8. Author's own calculations.

Table 8.7 Pooled multinomial logistic regression of change in sleep disturbance by caregiving transitions, women

	Improved sleep (t-2 to t)	Sleep disturbance onset	Stable sleep disturbance
Start caregiving	1.23 (0.72 - 2.11)	0.84 (0.43 - 1.62)	0.87 (0.46 - 1.64)
Continued caregiving	1.86 (0.94 - 3.69)	1.68 (0.79 - 3.58)	1.60 (0.79 - 3.25)
Ceased caregiving	1.36 (0.75 - 2.47)	1.72* (1.01 - 2.94)	2.35** (1.40 - 3.95)

Notes: 3,768 women with 6,422 observations; ref category for DV, stable low sleep disturbance; adjusted for age, age squared, wave, marital status, work status, non-housing wealth, physical activity, pain, limiting illness, self-rated health and depressive symptoms. * p<0.05, ** p<0.01, *** p<0.001; Estimated with robust standard errors; unweighted. Data source: ELSA, waves 3, 4, 5, 6, 7 and 8. Author's own calculations.

Table 8.8 Random effects and fixed effects LPMs of sleep disturbance by caregiving transition in care of 20 hours per week, men

	RE LPM, β coefficients			FE LPM, β coefficients		
	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, health excl depressive symp)	Model 3 (M2 + depressive symptoms)	Model 4 (covariates as M1)	Model 5 (covariates as M2)	Model 6 (covariates as M3)
Binary sleep disturbance						
Start 20+hr care	0.10* (0.02 – 0.19)	0.07 (-0.01 – 0.15)	0.06 (-0.01 – 0.14)	0.08 (-0.01 – 0.17)	0.07 (-0.02 – 0.17)	0.07 (-0.02 – 0.16)
Continued care	0.08 (-0.03 – 0.19)	0.06 (-0.05 – 0.16)	0.06 (-0.05 – 0.16)	0.05 (-0.09 – 0.19)	0.04 (-0.09 – 0.18)	0.05 (-0.09 – 0.19)
Cease 20+hr care	0.07 (-0.01 – 0.15)	0.04 (-0.04 – 0.12)	0.03 (-0.05 – 0.11)	0.05 (-0.04 – 0.15)	0.04 (-0.05 – 0.14)	0.05 (-0.05 – 0.14)

Notes: 3,003 men with 7,571 observations. Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); Estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, waves 3, 4, 5, 6, 7 and 8. Author's own calculations.

Table 8.9: Random effects LPM of sleep disturbance by caregiving duration of 20 hours care, women and men

	Random effects LPMs, β coefficients	
	Women, fully adjusted	Men, fully adjusted
1 wave care	0.00 (-0.03 – 0.04)	0.00 (-0.05 – 0.06)
2+ waves care	0.07* (0.02 – 0.13)	0.04 (-0.03 – 0.12)

Notes: Model 1 N: 3,768 women, Model 2 N: 3,003 men; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); * p<0.05, ** p<0.01, *** p<0.001; Estimated with robust standard errors; unweighted. Data source: ELSA, waves 3, 4, 5, 6, 7 and 8. Author's own calculations.

8.6 CONCLUSION

This chapter investigated associations with sleep disturbance, first, by transitions and stability over a caregiving episode, and second, by duration of care of one wave or two or more waves. Caregiving was measured as provision of 20 or more hours a week. Associations with sleep disturbance were found among women starting to provide care (imputed data), ceasing care or becoming a widow (complete case and imputed data, respectively) and for longer care duration. No similar patterns were found for men in complete case or imputed data. Specifically, among women, care cessation was associated with an increased probability of sleep disturbance in the main analyses. Sleep disturbance related to starting to provide care was found in sensitivity analysis using imputed data. In contrast to the main results, an association was not found with ceasing care using imputed data, however, becoming a widow was associated with sleep disturbance. These opposite results from complete case and imputed data indicate ceasing care and widowhood are closely related, bereavement one reason for care cessation. An association was found with consecutive care over two waves (as well as ceasing care) only when sleep disturbance was measured continuously. In relation to change in sleep disturbance, multinomial logistic regression analyses showed women ceasing care had a higher relative risk of developing sleep disturbance in the wave after ceasing care and of reporting stable sleep disturbance, prior to, and after, ceasing care, compared to non-caregivers. When care duration was analysed, caregiving for two or more waves, but not one wave, was associated with higher sleep disturbance among women.

The results from complete case analysis of transitions provide some support for previous studies which found no association between the start of care provision (Maun et al., 2020; Sacco et al., 2018) but links between ceasing care and sleep disturbance (Gerlich & Wolbring, 2021; van de Straat et al., 2021; von Kaenel et al., 2012). The existing literature shows limited consistency, however. Contrasting results have also indicated associations between starting care (Hajek & Koenig, 2022; van de Straat et al., 2021) and continued provision of care and poorer sleep (Maun et al., 2020; Sacco et al., 2018; van de Straat et al., 2021), as well as no linkage between ceasing care and sleep (Hajek & Koenig, 2022; Maun et al., 2020; von Kaenel et al., 2012). Results from analysis

of imputed data partially accord with those from a study of European mid- and late life adults finding greater odds of trouble sleeping among women than men at the start of care provision (van de Straat et al., 2021). In contrast to the results of this chapter, the two existing studies which assessed change in sleep disturbance found sleep disturbance improved once caregiving stopped, though not to the level of non-caregivers (Sacco et al., 2018; van de Straat et al., 2021). Differences compared to previous studies may be explained partially by differing samples and definitions of unpaid care, differing sleep measurements and shorter gaps between data points. For instance, studies focusing on similar aged adults included limited health covariates, used single item sleep questions and had only two- or three-year gaps between sleep measurements (Hajek & Koenig, 2022; van de Straat et al., 2021). Four-year gaps between ELSA sleep data could not capture more transient sleep changes, for instance, if sleep is disturbed for a shorter time at the start of care, before adjustment to an altered situation. In the analyses in this chapter, low frequency of transitions and the binary nature of sleep disturbance variable may have contributed to a reduced possibility of identifying associations, see Conclusions section 10.4. Considering care duration, the results from this chapter accord with two of five previous studies finding longer care duration to be associated with disturbed and short caregiver sleep (Liu et al., 2020; Simon et al., 2019). However, these studies compared longer care duration to shorter care duration, without comparison to non-caregivers.

The complete case results suggest sleep disturbance may increase after the end of a caregiving episode among women, as well as in the period prior to ceasing care. Distress and depressive symptoms have also been found to be elevated prior to ceasing care and continuing for periods of 15 months (Kaufman et al., 2019) and up to 4 years (Hirst, 2005). Prior to ceasing care, caregiving can be intensive and women's sleep may worsen, for instance, if there is a need to provide physical care at night or due to worry and anticipatory grief (Arber & Venn, 2011; Hislop & Arber, 2003a). End of life caregiving can involve unpredictable disease progression, challenging emotions, and preparation for death (Breen, L. J., Aoun, O'Connor, Howting, & Halkett, 2018). Sleep disturbance developed during this period can continue into widowhood for prolonged periods (Arber & Venn, 2011; Corey & McCurry, 2018). Care cessation due to moving a

family member to an institution, can also be emotionally and financially stressful (Pearlin & Aneshensel, 1994). Indeed, sleep disturbance can be a precipitating factor for such changes (Afram et al., 2014) and may continue following institutionalisation (Washington et al., 2018). In imputed analyses, widowhood rather than cessation of care was found to be associated with sleep disturbance. The two can be related where care cessation is due to bereavement. It is also important to note that neither widowhood nor caregiving transitions could be accurately measured. For instance, some diseases have a short and aggressive course (Kim & Schulz, 2008), caregiving in such circumstances may not be included in the data for the study. Results from imputed data also indicated an association between starting to provide care for 20 hours per week and sleep disturbance. Care provision may involve new and difficult tasks, changes to existing family relationships, or lead to worries about managing work or finances which could disturb sleep (Moral-Fernández et al., 2018).

Among men, given the associations found in chapter seven between care of 20 hours per week and spouse care, and sleep disturbance, it was surprising no associations were found with care transitions or periods of stability. However, the frequency of transitions among men was low in this chapter, which may reduce the possibility of detecting a smaller association (van den Broek & Grundy, 2018b). Alternatively in a population-based sample, sleep disturbances may be no more likely to occur than when not providing care: the associations in the last chapter were weak and not consistent across all analyses. As discussed above, sleep disturbances may also be more transitory in nature and therefore not well captured by this data (Kotronoulas et al., 2016). This is also the case for periods of caregiving that last less than two years. Differences in associations found compared to studies of other mid- and late life adults may be influenced by the wider social care environment in different countries. For instance, although country fixed-effects were included in analysis of SHARE data, accounting for between country differences in sleep disturbance (van de Straat et al., 2021), the association between unpaid care provision and sleep disturbance may vary by country, as found for caregiver quality of life (van den Broek & Grundy, 2018a). For instance, caregivers in southern European countries may be more likely to report sleep disturbance due to low levels of statutory alternatives to care when needed (Courtin,

Jemai, & Mossialos, 2014), illustrated by qualitative accounts of women in Italy (Bianchera & Arber, 2007).

Considering the analysis of care duration and sleep disturbance, sleep disturbance was associated with caregiving for two or more waves (four years), among women but not men. Longer care duration may involve care that becomes more burdensome, posing greater difficulties across other life domains over time (Kim & Schulz, 2008; Pearlin & Aneshensel, 1994), which might cause stress-related sleep disturbance. Further, sleep disturbance can be a symptom of some conditions requiring care of longer durations, for instance, neurological conditions or restlessness due to pain or medications in the case of many chronic conditions (Crowley, 2011; Kim & Schulz, 2008). Nevertheless, analysis of care duration was not able to take account of sleep disturbance prior to the start of care provision and individuals who go on to provide care for two or more years may already be more likely to have disturbed sleep.

Considered together, the results in this chapter indicate small increases in sleep disturbance among women providing care for two or more years and towards the end and after ceasing care. Widowhood was also associated with sleep disturbance. This could correspond to increasing strain, as well as the stress and anticipatory grief of losing a loved one. However, the results were based on analysis of a small number of transitions and some inconsistency was found in results from complete case and imputed data. The next chapter investigates partner health as a possible confounding factor by examining how changes in partner health are associated with sleep disturbance in the context of cohabitation and co-resident care.

Chapter nine - Co-resident caregiving, partner health and sleep among couples

9.1 INTRODUCTION

Caregiving is often carried out in the context of long-standing, interdependent relationships, particularly when caring for a partner (Moen, Robinson, & Dempster-McClain, 1995). Sleep practices and experiences develop and are sustained in the context of such relationships and may differ for women and men as a consequence of gendered social roles (Hislop & Arber, 2006; Meadows, 2005; Troxel, 2010).

Relationship characteristics, such as the health of both partners, may be important for sleep (Lee et al., 2018) and change in partner health is one possible reason for the provision of unpaid care (Bertogg & Strauss, 2020). Therefore, in the context of cohabiting couples, caregiving associations with sleep disturbance may be confounded by changes in a partner's health (Umberson & Thomeer, 2020). Partner poor health may disrupt a respondent's sleep due to the stress of having an ill partner, or due to partner night-time restlessness due to illness symptoms or medication side effects. Although small sections of the caregiving literature address partner health as a confounding factor in studies of caregiver health, no longitudinal population-based study of caregiver sleep has included partner health. This chapter aims to investigate how co-resident caregiving and partner health may be independently associated with sleep disturbance among cohabiting women and men. In addition, it analyses the first wave of ELSA data collected during the COVID-19 pandemic to assess whether relationships are evident with sleep quality (the sleep measure available in the COVID-19 data), in circumstances widely experienced as stressful. In doing so, the chapter aims to shed light on associations between co-resident caregiving and partner health on sleep disturbance and sleep quality in varying societal circumstances. The research questions addressed in this chapter are:

Research questions 5: among cohabiting women and men, how are co-resident care and partner health associated with sleep disturbance?

Research questions 6: How are co-resident care and partner health associated with sleep quality during the COVID-19 pandemic?

The chapter begins by providing an overview of the samples and statistical methods used to address the research questions (section 9.2). Descriptive statistics for English Longitudinal Study of Ageing, ELSA, wave 4 cross-sectional sample of couples and the longitudinal sample of waves 4, 6 and 8 are presented in section 9.3, followed by cross-sectional and longitudinal multivariable analysis in section 9.4. Descriptive statistics and multivariable analysis for the COVID-19 data is presented in section 9.5. The chapter ends by summarising and interpreting the results from all analyses in section 9.6.

9.2 SAMPLES AND ANALYTIC APPROACH

This chapter focuses on cohabiting partners following previous research (Bertogg & Strauss, 2020). Cohabitation is increasingly common in later life (Carr & Utz, 2020) and associated with similarly positive health differentials in psychological wellbeing (Brown & Wright, 2017) and sleep (Troxel et al., 2010), as for marriage²³(Umberson & Thomeer, 2020). Table 9.1 summarises the samples, analytic strategy and number of women and men used in analyses in the chapter. Analysis of couples comprised cross-sectional and longitudinal analysis of ELSA main survey data and cross-sectional analysis of COVID-19 data, see Descriptive statistics section 6.4 for full sample selection details. The samples for analysis of ELSA main survey data included individuals who were cohabiting with a spouse or partner, aged 50 or over, who also completed an interview. Individuals in same sex partnerships over the included waves (95 individuals) were excluded to allow stratification by gender in the longitudinal analysis²⁴. Wave 4 was used for a cross-sectional analysis of couples, including couples for whom each member had complete data on caregiving, sleep, partner health and covariates. The wave 4 cross-sectional sample included 4,546 individuals (2,273 women and men). The longitudinal analysis was of observations over waves, nested by individuals and the sample included

²³ The benefits of marriage have been found to be greater for men than women.

²⁴ A check was also run establishing whether any individuals changed gender during the study period.

individuals for whom complete personal data and partner health data was available in at least two waves from waves 4, 6 and 8. Partner data included diagnosed conditions and number of ADL difficulties and data from partners whose response was provided by proxy were included. This was important as partners using a proxy interview might require more intensive care than partners with capacity to carry out an interview. A flag for proxy partner was used to check how change to proxy partner status changed results (see section 9.3). Individuals whose partnership status changed over the included waves were also excluded from the sample (207 individuals), so that changes in partner health could be attributed to changing health status rather than a change in partner. The longitudinal sample included 4,790 individuals (2,406 women and 2,384 men), with 12,461 observations across the three waves: 4,181 at wave 4, 4,633 at wave 6, and 3,647 at wave 8. See Figure 6.3 and 6.4, chapter six for further sample selection details.

The cross-sectional analysis of COVID-19 sub-study data is presented in section 9.5. The sample included individuals with complete data from COVID-19 sub-study wave 1 for the relevant variables including partner health, and wealth, self-rated health, education, and children in the household data from ELSA wave 9. In the COVID-19 data, no variables were available differentiating respondent and partner, therefore household code and gender were used to identify cohabiting individuals. Following this strategy, same-sex couples were excluded, consistent with the longitudinal analysis, but some individuals cohabiting with a member of the opposite sex other than a spouse or partner may remain. The final sample included 3,843 individuals (1,413 men and 1,430 women).

As noted in Descriptive statistics section 6.4, there were significant differences between the longitudinal sample selected and the dropped observations from all cohabiting couples: the sample was older and less likely to be renting, have a mortgage or be in the lowest two wealth quintiles. Additionally, they were healthier than those cohabiting individuals who were dropped. Co-resident caregivers were less likely to be included in the sample. Dropped co-resident caregivers had less than two waves of complete data and almost all looked after spouses. A similar number looked after proxy to non-proxy

responding partners (10% of dropped cases, 9% of those in sample). The COVID-19 sample was older, more likely to include females and less likely to have individuals with depressive symptoms compared to the dropped cases.

Table 9.1: Number of cases and observations for analyses

	ELSA main survey		COVID-19 sub-study
Data	Cross-sectional, wave 4	Longitudinal, 2+ waves from wave 4, 6 or 8	Cross-sectional, wave 1
Analysis	Multilevel modelling of couple data†	Fixed effects linear probability	Logistic regression
Women N (obs)	2,273	2,406 (6,225)	1,430
Men N (obs)	2,273	2,384 (6,236)	1,413
Imputed data††			
Women N (obs)	N/A	3,589 (10,767)	N/A
Men N (obs)	N/A	3,488 (10,464)	N/A

† data was set to individuals nested within households

†† sensitivity analysis in Appendix F

Abbreviations: obs, observations

Descriptive statistics for the cross-sectional sample of couples by gender used design-based F statistics for categorical variables and t-tests from regression models for continuous variables on weighted data, Table 9.2. Description of the longitudinal sample of couples was carried out unweighted as no suitable weight was available for the pooled sample, see Methodology section 5.4.1. Individuals ever having provided co-resident care over the three waves were compared to those never providing co-resident care. Chi-squared tests were carried out for categorical variables and t-tests for continuous variables, Table 9.3. Gender-stratified fixed effects linear probability models, FE LPMs, measured associations between co-resident care, partner health and sleep disturbance. In the second half of the chapter, analysis was carried out using data from wave 1 of the ELSA COVID-19 sub-study. Descriptive analyses were carried out as for the main survey data, describing characteristics by gender and by co-resident care status. Logistic regression analysis assessed cross-sectional associations between co-resident care, partner health and sleep quality using the longitudinal weight provided (due to the need to use wave 9 data for some variables). Model covariates differed slightly to the previous two chapters as analysis was carried out for cohabiting couples. In these analyses household characteristics were controlled more fully to account for

possible sources of alternative care, such as presence of children in the household, unpaid care from an individual other than a spouse and receipt of formal care, see Methodology sections 5.3 and 5.4.4.

9.3 DESCRIPTIVE STATISTICS

Table 9.2 summarises the sample for the cross-sectional analysis of couples in wave 4, stratified by gender. As with the other samples in this thesis, sleep disturbance measured using the sex-specific binary measure was lower for women (22%) than men (29%), though this was partially an artefact of classification, see Methodology section 5.3. There were no differences in the distribution of co-resident care by gender. Unlike the samples of previous chapters, women were younger (mean 64 years) than men (66 years), as more older women were dropped from this sample of couples. Women's longer life expectancy, lower rates of remarriage and cohabitation following widowhood, in addition to men tending to marry younger women are likely explanations for this (Office for National Statistics, 2018; 2020b). A smaller percentage of women had a degree or were in paid work than men. Women were also significantly more likely than men to report pain, to take less physical activity and have high depressive symptoms (15% compared to 9%). Among partner health characteristics, male partners of female respondents were more likely to have each health condition than female partners of male respondents, apart from arthritis. For example, 13% of male partners reported a heart condition, compared to 6% of female partners; while only 28% of male partners reported arthritis compared to 39% of female partners. There were no gender differences in partner diagnoses of cancer and total ADL difficulties or total number of conditions. Compared to the baseline sample for wave 4, described in section 6.3 of chapter six, the sample for this chapter included fewer individuals in the lowest two wealth quintiles. For instance, 14% of the sample described in Table 9.2 were in the lowest wealth quintile, compared to 20% of the baseline sample, Table 6.1). In addition, fewer individuals with fair or poor self-rated health or depressive symptoms were included in the sample for this chapter. For instance, 23% of women reported fair or poor self-rated health in Table 9.2, compared to 28% in Table 6.1. This might be expected as married and cohabiting couples benefit from financial resources from both individuals in the couple, and have been found to

have better health than individuals with other marital status (Umberson & Thomeer, 2020).

Table 9.3 presents descriptive statistics for the longitudinal sample, stratified by gender and comparing individuals who did not report providing co-resident care over the three waves, with individuals who reported providing co-resident care in at least one wave. Among women, those who ever provided co-resident care were more likely to report sleep disturbance (25%) than those never providing care (20%). Women who ever provided co-resident care were also older, more likely to report pain, limiting illness, fair or poor self-rated health and have 3 or more depressive symptoms (17% compared to 12%). Unsurprisingly, the partners of women ever providing co-resident care had worse health than the partners of women not providing any co-resident care in the three waves. For instance, partners of women ever providing co-resident care had a mean of 1.3 ADL difficulties (standard deviation, sd:1.6), compared to 0.17 difficulties (sd:0.6) among those never providing care. Almost all co-resident caregivers provided care to their spouse, but 5% received care themselves from their spouse, while 2% provided care with their partner to another member of the household.

Among men, there were no significant differences in sleep disturbance by co-resident caregiving. However, men who had ever provided co-resident care over the three waves were older and significantly less healthy than men who had not provided care. For instance, 40% reported a limiting long-standing condition (compared to 29% among never caregivers). As among women, the partners of men who had ever provided care had significantly worse health. Overall, except for arthritis, the female partners of the male respondents had fewer health conditions than the male partners of female respondents, possibly linked to the older average age of male partners. Among both genders, individuals who ever provided co-resident care were more likely to live in a household receiving other sources of formal and informal care, to live in rented accommodation and to be in the lowest wealth quintile.

To check sufficient change was available in model coefficients across waves to allow fixed effects models to be performed, within and between variation analysis was conducted. Results are presented in Table 9.4 for co-resident care and categorical partner health variables and Table 9.5 for continuous partner health variables. Frequency of transitions are also noted in Appendix F1. As for other caregiving characteristics, the prevalence of co-resident caregiving was low (5% of observations among women and 4% among men). However, the between variation indicated that 10% of women and 8% of men had ever been a co-resident caregiver, and sufficient within variation was available for fixed effects models. Of partner diagnosed conditions, there were few observations of neurological disease among women and men but more within-person variation (more partners being diagnosed) than for heart and lung conditions and arthritis, which were more prevalent, but also more stable. Appendix F1 indicates within-person change coefficients for partner neurological disease in the longitudinal models are based on 86 transitions in women and 54 in men. The number of transitions for lung disease was also low among men (49). As noted in section 8.3, the low frequency of transitions is a limitation of the available data, important to note for the subsequent results (van den Broek & Grundy, 2018b).

Table 9.2 Characteristics of couples, by gender, wave 4

		Women	Men	P value
Respondent variables	Sleep disturbance %	21.7	28.9	<0.001
	Sleep quality % †	25.4	14.8	<0.001
	Co-resident care %	4.6	3.7	0.1
	Age mean, sd	64.2	66.0	<0.001
	Degree	12.2	20.6	
	Intermediate	56.5	56.1	
	No qualifications	31.3	23.4	<0.001
	In paid work	40.7	49.1	<0.001
	Non-limiting illness	19.8	22.8	
	Limiting illness	31.6	31.5	0.03
	Moderate or strong pain	31.1	23.8	<0.001
	< Once a week activity	37.0	32.8	<0.001
	Fair or poor SRH	22.8	24.6	0.1
	3+ depressive symptoms	15.0	9.4	<0.001
Partner health	Partner neurological condition	1.9	1.0	0.01
	Partner cancer	3.9	3.1	0.1
	Partner arthritis	28.2	38.8	<0.001
	Partner lung disease	5.5	3.6	0.003
	Partner heart condition††	13.1	5.6	<0.001
	Partner total conditions, mean (se)	1.7 (0.03)	1.6 (0.03)	0.05
	Partner total ADL difficulties, mean (se)	0.3 (0.02)	0.3 (0.02)	0.6
Household variables	Formal and informal care	2.4		
	2 nd wealth quintile	22.6		
	Middle quintile	22.3		
	2 nd lowest quintile	17.9		
	Lowest wealth quintile	13.8		
	Mortgage	20.2		
	Renting	9.2		
	Household size, mean (se)	2.3 (0.01)		
	Children live outside hhd	67.8		
Children live in hhd	25.7			

Notes: 4,526 individuals in 2,273 couples. weighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, wave 4. † sleep quality noted for comparison to COVID-19 sample, section 9.4; †† partner heart condition, defined as diagnosed angina or myocardial infarction; significance tests: design-based F statistics and t-tests (continuous variables)

Table 9.3 Characteristics stratified by never and ever providing co-resident care, waves 4, 6 and 8

Variable	Proportion of sample/mean (se), all observations, unweighted			
	Women		Men	
	Never a co-resident caregiver Obs=5,586 (90%)	Ever a co-resident caregiver Obs=639 (10%)	Never a co-resident caregiver Obs=5,732 (92%)	Ever a co-resident caregiver Obs=504 (8%)
Respondent variables				
Disturbed sleep (binary)	19.6	25.0 **	28.0	31.8
Poor sleep quality % †	24.0	31.0 ***	14.6	16.3
Mean age (sd)	65.9 (7.9)	67.8 (8.4) ***	67.7 (8.4)	70.5 (8.6) ***
Not in work	65.3	67.1	54.6	66.9
In paid work	34.7	32.9	45.4	33.1***
No illness	48.7	44.3	46.3	37.7
Non-limiting ill	20.9	18.5	24.8	21.4
Limiting illness	30.4	37.3**	28.8	39.9***
No/weak pain	69.6	60.3	78.2	69.6
Moderate/severe pain	30.4	39.8***	21.8	30.4***
>=once per week activity	67.1	63.2	71.6	64.3
<once per week activity	32.9	36.8	28.4	35.7**
Good or better health	79.1	74.7	77.4	68.3
Fair or poor health	20.9	25.4*	22.6	31.8***
CES-D adapted <=2	87.7	82.8	92.8	87.7
>=3 symptoms	12.3	17.2***	7.2	12.3***
Partner health variables				
Partner total conditions, mean (sd)	1.86 (1.6)	3.38 (2.3)***	1.74 (1.5)	3.14 (2.1)***
Partner total ADL diffs, mean (sd)	0.17 (0.6)	1.33 (1.6)***	0.16 (0.6)	1.33 (1.7)***

Partner heart conditions	13.6	28.9***	5.3	18.0***
Partner neurological cond	2.1	12.8***	1.1	6.9***
Partner cancer	4.2	9.9***	3.0	6.8***
Partner lung disease	5.3	17.5***	3.2	8.7***
Partner arthritis	29.8	53.4***	40.4	64.9***
Household variables				
Formal and informal care	1.3	6.9 ***	1.3	8.1***
Household size	2.2 (0.6)	2.2 (0.5)	2.3 (0.7)	2.2 (0.5)***
Own outright	76.2	76.4	76.2	77.0
Mortgage	16.6	10.8	17.4	10.7
Renting	7.1	12.8***	6.4	12.3***
Highest wealth	29.0	19.6	28.3	22.0
2 nd highest	25.7	19.4	25.8	23.2
Middle	21.0	23.9	21.0	19.3
2 nd lowest	14.8	19.4	15.0	20.4
Lowest wealth	9.5	17.7***	9.9	15.1***
No children	7.0	10.8	7.9	7.5
Children outside hhd	71.0	75.3	69.1	77.2
Children living in hhd	22.0	13.9***	23.0	15.3***
Solo care		93.4		92.9
Mutual spouse care		4.9		5.2
Both care for 3 rd person		1.7		2.0

Notes: 2,406 women with 6,225 observations; 2,384 men with 6,236 observations. Unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, waves 4, 6 and 8; significance tests: Chi squared (categorical) and t-tests (continuous variables); author's own calculations.

Table 9.4 Variation in co-resident care and partner health, women and men

	Variation across three waves			
	Overall person/waves % (obs)	Between variation (ever been) % (N)	Within variation (% stable for ever reported)	Overall stability (average within variation)
Women (N=2,406)				
No care/non-res care	94.9 (5,907)	98.7 (2,374)	96.0	91.8
Co-resident care	5.1 (318)	10.3 (247)	51.6	
Partner neurol disease	3.2 (199)	5.3 (127)	62.1	96.5
Partner cancer	4.8 (300)	9.9 (237)	49.7	92.0
Partner heart condition	15.5 (965)	19.8 (476)	79.2	91.9
Partner lung disease	6.6 (408)	8.9 (213)	75.4	95.8
Partner arthritis	32.3 (2,008)	37.8 (909)	84.4	89.3
Men (N=2,384)				
No care/non-res care	96.0 (5,989)	99.0 (2,361)	96.9	93.4
Co-resident care	4.0 (247)	8.0 (191)	50.5	
Partner neurol disease	1.6 (97)	2.9 (70)	56.7	97.7
Partner cancer	3.3 (208)	7.2 (172)	47.1	93.8
Partner heart condition	6.6 (414)	9.0 (214)	74.4	95.2
Partner lung disease	3.7 (229)	4.7 (113)	76.3	97.9
Partner arthritis	42.3 (2,640)	50 (1,189)	84.4	86.4

Data source: ELSA, waves 4, 6 and 8. Author's own calculations. Unweighted. Abbreviations: obs, observation; non-res, non-resident.

Table 9.5 Variation in partner total conditions and ADL difficulties, women and men

	Mean	Overall standard deviation, sd	Between sd (% of total)	Within sd (% of total)	Overall stability (between variation as % total variation)
Women (N=2,406)					
Partner conditions	2.01	1.78	1.66 (93.3)	0.68 (38.2)	87.0
Partner ADLs	2.98	0.87	0.73 (83.9)	0.49 (56.3)	70.4
Men (N=2,384)					
Partner total cond	1.85	1.62	1.50 (92.5)	0.63 (38.0)	85.7
Partner total ADLs	2.56	0.82	0.71 (86.5)	0.43 (52.4)	75.0

Data source: ELSA, waves 4, 6 and 8. Author's own calculations. Unweighted. Abbreviations: sd, standard deviation

9.4 ASSOCIATIONS BETWEEN CO-RESIDENT CAREGIVING, PARTNER HEALTH AND SLEEP

9.4.1 Cross-sectional analysis

Table 9.6 provides results from the multilevel linear probability models of couple data from wave 4, accounting for the correlation between couple sleep disturbance. In unadjusted model (Model 1), there was a 24% probability of reporting sleep disturbance in the sample. Variation in sleep disturbance explained by being in a couple was measured using the intra-class correlation coefficient (ICC) (Rabe-Hesketh & Skrondal, 2012), provided at the bottom of Table 9.6, see Appendix B2. Ten percent of the variation in sleep disturbance responses could be accounted for at the couple level in the unadjusted model (ICC: 0.10, se 0.02, Model 1). Accounting for couple level variation, compared to a linear probability model without couple clustering, was significant ($X^2(1) = 24.1, p < 0.001$). In Model 2, adding individual characteristics, there was no evidence of an association between co-resident care provision and sleep disturbance (consistent across Models 3 and 4). Increased probability of sleep disturbance was found among those who were younger, male and in poorer health, and these individual factors reduced the variation attributed to the couple level (ICC 0.06, se 0.02, Model 2). Living in rented accommodation was the only household characteristic associated with sleep disturbance, added in Model 3. In the final model, Model 4, partner health variables were added. No associations were found with partner conditions previously associated with disturbed sleep (cancer, neurological conditions, lung disease, arthritis, heart disease), partner total number of conditions or ADL difficulties. Given the variables in the full model, 6% (se 0.02) of the variation in sleep disturbance was still attributed to being in a couple. A similar percentage of the variation in sleep responses²⁵ has been attributed to being in a couple, in a previous analysis of UK adults aged over 50 (Meadows & Arber, 2011). The latter study analysed daily couple data and included data on snoring, potential bed-sharing and previous cohabitations. Other shared factors, such as bedroom environment and neighbourhood characteristics, may also be important (Hale et al., 2013). When interpreting the results of the gender-stratified models in this chapter, it is important to consider that there

²⁵ The study measured trouble sleeping for 3 or more nights per week due to waking in the middle of the night or early in the morning

may be changes in sleep disturbance associated with couple level factors which are not captured in the longitudinal analyses. The next section analyses whether change in co-resident care and new partner health conditions are associated with sleep disturbance, using longitudinal data.

9.4.2 Longitudinal analysis

This section discusses the analysis of longitudinal data using ELSA waves 4, 6 and 8, to investigate associations between co-resident caregiving, partner health and sleep disturbance in the period 2008/9 to 2016/17. Gender-stratified fixed effects linear probability models (FE LPMs) were adjusted for respondent demographic, work and health factors (Model 1), household factors (Model 2) and partner health factors (Model 3). Results are displayed in Table 9.7 for women and Table 9.8 for men. Coefficients represent the probability of sleep disturbance with a change in status in a given individual (categorical variables) or a one-unit change (continuous). Among women, results indicated within-person changes in co-resident care were not associated with sleep disturbance in any model. As in previous chapters, change in experiencing moderate pain and high depressive symptoms was associated with sleep disturbance among cohabiting women (Model 1). Unlike previous analyses, fair or poor self-rated health was not associated with sleep disturbance. Among household factors added in Model 2, only within-person change moving into the lowest wealth quintile was associated with sleep disturbance (Model 2, β coefficient 0.08, CI 0.95: 0.01 – 0.14). In Model 3, with the addition of partner health, a woman who newly reported her partner being diagnosed with a neurological condition, had a 15% higher probability of reporting sleep disturbance in the fully adjusted model (Model 3, β coefficient 0.15, CI 0.95: 0.06 – 0.24). It is important to note the coefficient was calculated based on 86 partners being newly diagnosed with a neurological disease, Appendix Table F1, and the confidence interval was wide for this estimate. No other partner diagnosis or increase in the number of diagnosed conditions or partner ADL difficulties were associated with women's sleep disturbance. As the sample included individuals whose partners were proxy respondents, this last model was re-run including a flag for proxy respondent, but results did not change (not shown). Consistent results were found when the final model was re-run on imputed data, Table F2.

Among men, Table 9.8, a small increased probability of sleep disturbance was found for within-person change in co-resident care, of the same magnitude as found in chapter seven, adjusted for individual characteristics (Model 1). The association lost significance with the addition of household characteristics (Model 2). When partner diagnosed conditions, total number of conditions and ADL difficulties were added the coefficient did not change (Model 3). As in previous analyses, limiting illness, fair or poor self-rated health and depressive symptoms were associated with sleep disturbance. Neither having a partner newly diagnosed with a condition associated with disturbed sleep nor change in a partner's total number of conditions and number of ADL difficulties were associated with male respondent sleep disturbance, Model 3. The results from this final model did not change when re-run on imputed data.

Table 9.6: Multilevel linear probability regression of sleep disturbance by co-resident care, partner health and covariates, couples, wave 4

	Model 1 – unconditional ICC	Model 2 – respondent variables	Model 3 – couple variables	Model 4 – partner health variables
Individual characteristics				
Co-resident care		0.03 (-0.03 - 0.09)	0.03 (-0.04 - 0.09)	0.02 (-0.05 - 0.09)
Age		-0.00*** (-0.00 - -0.00)	-0.00*** (-0.00 - -0.00)	-0.00*** (-0.00 - -0.00)
Female		-0.10*** (-0.12 - -0.07)	-0.09*** (-0.12 - -0.07)	-0.09*** (-0.12 - -0.07)
Intermediate		0.01 (-0.01 - 0.04)	0.01 (-0.02 - 0.04)	0.01 (-0.02 - 0.04)
No qualifications		0.04 (-0.00 - 0.08)	0.02 (-0.01 - 0.06)	0.02 (-0.01 - 0.06)
In paid work		0.00 (-0.03 - 0.03)	-0.00 (-0.03 - 0.02)	-0.00 (-0.03 - 0.03)
Non-limiting illness		0.02 (-0.00 - 0.05)	0.02 (-0.00 - 0.05)	0.02 (-0.00 - 0.05)
Limiting illness		0.09*** (0.05 - 0.12)	0.09*** (0.05 - 0.12)	0.09*** (0.05 - 0.12)
No or weak pain		0.09*** (0.06 - 0.12)	0.09*** (0.06 - 0.12)	0.09*** (0.06 - 0.12)
<once a week activity		0.00 (-0.02 - 0.03)	-0.00 (-0.02 - 0.03)	-0.00 (-0.03 - 0.03)
Fair or poor self-rated health		0.11*** (0.08 - 0.15)	0.11*** (0.07 - 0.15)	0.11*** (0.07 - 0.15)
High depressive symptoms, 3+		0.20*** (0.15 - 0.25)	0.20*** (0.15 - 0.24)	0.20*** (0.15 - 0.24)
Partner health				
Partner neurological diagnosis				0.01 (-0.09 - 0.11)
Partner cancer diagnosis				0.01 (-0.06 - 0.08)
Partner heart condition diagnosis				-0.01 (0.05 - 0.04)
Partner lung disease				0.01 (-0.06 - 0.08)
Partner arthritis				0.02 (-0.01 - 0.05)
Partner total conditions (n)				0.01 (-0.01 - 0.02)
Partner total ADL diff (n)				-0.00 (-0.02 - 0.00)
Couple characteristics				
Formal and informal care			-0.04 (-0.15 - 0.06)	-0.05 (-0.15 - 0.06)
Mortgage			0.02 (-0.01 - 0.06)	0.02 (-0.01 - 0.06)

Renting			0.07* (0.01 – 0.12)	0.06* (0.01 – 0.12)
Second wealth quintile			0.00 (-0.02 – 0.04)	0.01 (-0.02 – 0.04)
Middle quintile			0.03 (-0.01 – 0.06)	0.03 (-0.01 – 0.06)
Second lowest			0.01 (-0.02 – 0.05)	0.01 (-0.02 – 0.05)
Lowest wealth quintile			0.03 (-0.02 – 0.08)	0.03 (-0.02 – 0.08)
Household size			-0.01 (-0.04 – 0.02)	-0.01 (-0.04 – 0.02)
Children outside hhd			-0.03 (-0.08 – 0.02)	-0.03 (-0.08 – 0.02)
Children living in hhd			-0.01 (-0.07 – 0.05)	-0.01 (-0.07 – 0.06)
Constant	0.24*** (0.23 – 0.25)	0.42*** (0.30 – 0.55)	0.40*** (0.24 – 0.55)	0.39*** (0.24 – 0.55)
Variation between couples	0.02	0.01	0.01	0.01
Variation within couples	0.17	0.15	0.15	0.15
Intra Class Correlation (se)	0.10 (0.02)	0.06 (0.02)	0.06 (0.02)	0.06 (0.02)

Notes: 4,546 individuals, 2,273 couples. Reference groups: no co-resident care; degree; not in paid work; no long-standing illness; good or better SRH; <2 depressive symptoms; no diagnosis; own property outright; highest wealth quintile; no children. Estimated with cluster robust standard errors; weighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: English Longitudinal Study of Ageing, Wave 4. Author's own calculations.

Table 9.7: Fixed effects LPMs of sleep disturbance by co-resident care and partner health characteristics, women

	Model 1 – respondent variables	Model 2 – M1 + couple variables	Model 3 – M2 + partner health variables
Co-resident care	0.04 (-0.02 – 0.10)	0.04 (-0.01 – 0.10)	0.03 (-0.03 – 0.09)
Age	-0.01 (-0.05 – 0.03)	-0.00 (-0.04 – 0.03)	0.00 (-0.04 – 0.04)
Age squared	0.00 (-0.00 – 0.00)	0.00 (-0.00 – 0.00)	0.00 (-0.00 – 0.00)
Wave 6	0.00 (-0.11– 0.10)	-0.01 (-0.11– 0.10)	-0.01 (-0.12– 0.09)
Wave 8	-0.03 (-0.24 – 0.18)	0.04 (-0.25 – 0.17)	-0.05 (-0.26 – 0.16)
Working	0.01 (-0.02 – 0.04)	0.01 (-0.02 – 0.04)	0.01 (-0.02 – 0.04)
Non-limiting illness	-0.01 (-0.04 – 0.02)	-0.01 (-0.04 – 0.02)	-0.01 (-0.04 – 0.02)
Limiting illness	0.02 (-0.01 – 0.06)	0.02 (-0.01 – 0.06)	0.02 (-0.01 – 0.06)
Moderate/severe pain	0.04* (0.00 – 0.07)	0.04* (0.01 – 0.07)	0.04* (0.01 – 0.07)
<Weekly moderate/vigorous activity	0.02 (-0.00 – 0.05)	0.02 (-0.01 – 0.05)	0.02 (-0.00 – 0.05)
Self-rated health	0.04 (-0.00 – 0.08)	0.04 (-0.00 – 0.08)	0.04 (-0.00 – 0.08)
High depressive symptoms, 3+	0.08*** (0.04 – 0.13)	0.08*** (0.04 – 0.12)	0.08*** (0.03 – 0.12)
Partner neurological diagnosis			0.15** (0.06 – 0.24)
Partner cancer diagnosis			0.05 (-0.02 – 0.11)
Partner heart condition diagnosis			0.03 (-0.02 – 0.08)
Partner lung disease			0.02 (-0.07 – 0.10)
Partner arthritis			-0.02 (-0.07 – 0.03)
Partner total conditions (n)			-0.00 (-0.02 – 0.01)
Partner ADL difficulty (n)			-0.00 (-0.02 – 0.02)
Formal and informal care		0.03 (-0.06 – 0.12)	0.02 (-0.08 – 0.11)
2 nd highest wealth quintile		-0.00 (-0.03 – 0.03)	-0.00 (-0.03 – 0.03)
Middle quintile		-0.01 (-0.04 – 0.03)	-0.01 (-0.04 – 0.03)

2 nd lowest	0.00 (-0.04 – 0.05)	0.00 (-0.03 – 0.03)
Lowest quintile	0.08* (0.01 – 0.14)	0.08* (0.01 – 0.14)
Mortgage	0.02 (-0.03 – 0.06)	0.02 (-0.03 – 0.06)
Renting	-0.14 (-0.30 – 0.02)	-0.14 (-0.30 – 0.02)
Household size	0.00 (-0.03 – 0.03)	0.00 (-0.03 – 0.03)
Children living outside house	-0.08 (-0.18 - 0.02)	-0.07 (-0.17 - 0.02)
Co-resident children	-0.07 (-0.17 – 0.02)	-0.07 (-0.17 – 0.02)

Notes: 2,406 women with 6,225 observations; Reference groups: no co-resident care; wave 4; not in paid work; no long-standing illness; no or weak pain; moderate or vigorous exercise once a week or more; good or better SRH; 2 or fewer depressive symptoms; no diagnosis; own property outright; no household care receipt; highest wealth quintile; no children. Estimated with cluster robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, waves 4, 6 and 8. Author's own calculations.

Table 9.8: Fixed effects LPMs of sleep disturbance by co-resident care and partner health characteristics, men

	Model 1 - individual vars	Model 2 - M1 + couple vars	Model 3 - M2 + partner health
Co-resident care	0.07* (0.00 - 0.14)	0.07 (-0.00 - 0.14)	0.06 (-0.01 - 0.13)
Age	-0.03 (-0.07 - 0.01)	-0.03 (-0.07 - 0.02)	-0.03 (-0.07 - 0.02)
Age squared	0.00 (-0.00 - 0.00)	0.00 (-0.00 - 0.00)	0.00 (-0.00 - 0.00)
Wave 6	0.09 (-0.00 - 0.19)	0.09 (-0.00 - 0.18)	0.09 (0.01 - 0.18)
Wave 8	0.17 (-0.01 - 0.35)	0.17 (0.01 - 0.35)	0.18 (-0.00 - 0.36)
Working	0.01 (-0.02 - 0.04)	0.01 (-0.02 - 0.04)	0.01 (-0.02 - 0.04)
Non-limiting illness	0.00 (-0.04 - 0.03)	-0.00 (-0.04 - 0.03)	-0.00 (-0.04 - 0.03)
Limiting illness	0.05** (0.02 - 0.10)	0.05** (0.01 - 0.10)	0.05** (0.01 - 0.09)
Moderate/severe pain	0.06** (0.02 - 0.10)	0.06** (0.02 - 0.10)	0.06** (0.02 - 0.10)
<Weekly moderate/vigorous activity	-0.01 (-0.03 - 0.02)	-0.01 (-0.04 - 0.02)	-0.01 (-0.04 - 0.02)
Self-rated health	0.06* (0.01 - 0.10)	0.05* (0.01 - 0.10)	0.06* (0.01 - 0.10)
High depressive symptoms, 3+	0.09*** (0.04 - 0.15)	0.09** (0.04 - 0.15)	0.09** (0.04 - 0.15)
Partner neurological diagnosis			0.04 (-0.09 - 0.17)
Partner cancer diagnosis			0.00 (-0.08 - 0.10)
Partner heart condition diagnosis			0.00 (-0.08 - 0.08)
Partner lung disease			-0.08 (-0.21 - 0.05)
Partner arthritis			-0.02 (-0.07 - 0.03)
Partner total conditions (n)			-0.00 (-0.02 - 0.02)
Partner ADL difficulty (n)			0.01 (-0.02 - 0.03)
Formal and informal care		0.02 (-0.10 - 0.13)	0.01 (-0.11 - 0.13)
2 nd highest wealth quintile		0.02 (-0.02 - 0.05)	0.02 (-0.02 - 0.05)
Middle quintile		0.04 (-0.00 - 0.09)	0.04 (-0.00 - 0.09)

2 nd lowest	0.02 (-0.03 – 0.09)	0.02 (-0.03 – 0.08)
Lowest quintile	-0.01 (-0.08 – 0.06)	-0.01 (-0.08 – 0.06)
Mortgage	-0.01 (-0.05 – 0.04)	-0.01 (-0.05 – 0.04)
Renting	-0.12 (-0.34 – 0.10)	-0.12 (-0.34 – 0.10)
Household size	0.00 (-0.03 – 0.04)	0.00 (-0.03 – 0.04)
Children living outside house	0.05 (-0.07 – 0.17)	0.05 (-0.07 – 0.17)
Co-resident children	0.05 (-0.07 – 0.17)	0.05 (-0.07 – 0.17)

Notes: 2,384 men with 6,236 observations; Reference groups: no co-resident care; wave 4; not in paid work; no long-standing illness; no or weak pain; moderate or vigorous activity once or more per week; good or better SRH; no diagnosis; own property outright; no household care receipt; highest wealth quintile; no children. Estimated with cluster robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, waves 4, 6 and 8. Author's own calculations.

9.5 CO-RESIDENT CAREGIVING, PARTNER HEALTH AND SLEEP QUALITY DURING THE COVID-19 PANDEMIC

This section addresses the final research question: are similar relationships found between co-resident care, partner health and sleep quality during the coronavirus pandemic? It uses the first wave of ELSA COVID-19 sub-study data collected during June and July 2020, the early months of the COVID-19 pandemic.

9.5.1 Descriptive statistics

Table 9.9 describes the ELSA COVID-19 sub-study wave 1 sample of cohabiting women and men, stratified by gender. In comparison to the sample of couples from ELSA wave 4, in section 9.3, a much higher proportion of women and men reported poor sleep quality during the coronavirus pandemic (45% women and 35% men, Table 9.9, compared to 25% and 15%, Table 9.2). This accords with evidence of declining sleep quality and greater sleep disturbance in other coronavirus data (Wright et al., 2021). Levels of co-resident care were also higher than in the cross-sectional sample of wave 4 data (13% women and 8% men in Table 9.9, compared to 5% and 4%, Table 9.2). The definition of co-resident care is less comparable to the main survey sample, as COVID-19 sub-study caregiving questions referred to the period of the pandemic, while co-resident caregivers in the main survey sample were defined as those who reported providing care in the last month and last week. However, the increase is consistent with other data (Office for National Statistics, 2020a). Health measures were comparable across samples apart from depressive symptoms, where the proportion of both genders reporting 3 or more depressive symptoms was almost double in the COVID-19 data. This is even more striking as the COVID-19 depressive symptoms measure does not include the commonly reported symptom “feeling sad” due to survey issues (see Methodology section 5.3). Interestingly, almost a quarter of co-resident caregivers had a partner who also reported providing co-resident care in the same household. Most of these co-resident caregivers whose partner also provided co-resident care lived in two person households, indicating they looked after each other. The remainder lived in larger households, suggesting they looked after a parent or other relative (figures not shown). A recently published study of co-resident care and mental health among UK adults during April and July 2020 also found high levels of shared care: 35% of co-

resident caregivers shared care (Whitley, Reeve, & Benzeval, 2021). The definition of care used in the study included care to a sick or disabled child, a likely reason why shared care was even higher than in the COVID-19 data used in this chapter. In fact, mutual care was found to be much higher in ELSA COVID-19 data than in the longitudinal sample analysed in the first half of this chapter²⁶. This may indicate a differing interpretation of co-resident caregiving during the pandemic, particularly when considering responses related to COVID-19 vulnerability and shielding discussed below.

Table 9.10 stratifies the sample by those not providing co-resident care and those providing co-resident care during the pandemic, indicating their differing circumstances. Co-resident caregivers were more likely to have poor sleep than non-caregivers (49% versus 39%, Table 9.10). Co-resident caregivers were older, more likely to be in the lowest wealth quintile, have poorer physical and mental health and to have a partner with a health condition. In the context of the pandemic, these are characteristics and circumstances that may be a significant source of stress. For instance, they were more likely to be personally vulnerable to COVID-19 (23% compared to 12% of non-caregivers). Unsurprisingly, as at least one member of the couple had a need for care, co-resident caregivers were also more likely to be in a household where one or both individuals had isolated during April or July or were identified as vulnerable to the coronavirus by their GP. These characteristics and COVID-19-related difficulties might suggest reasons co-resident caregivers might experience new stressors and caregiving stressors may be exacerbated during the pandemic and could be associated with sleep disturbance as a possible consequence of such stress.

²⁶ In the longitudinal sample, 7% of co-resident caregivers had a partner who also provided co-resident care, either for each other or for another individual (Table 9.3)

Table 9.9: Characteristics of couples by gender, COVID-19 wave 1

		Women N=1,430	Men N=1,413	P value
Respondent variables	Poor sleep quality %	44.8	35.1	<0.001
	Co-resident care %	12.6	8.4	0.003
	(Both provide care	2.5	2.2)	0.003
	Age mean, sd	66.2	67.7 (0.34)	<0.001
	In paid work	23.9	31.0	<0.001
	Non-limiting illness	18.8	24.5	
	Limiting illness	28.7	26.8	0.008
	Fair or poor SRH	21.0	18.9	0.2
	3+ depressive symptoms	27.2	17.3	<0.001
Partner health	Partner neurological condition	2.7	1.4	0.01
	Partner cancer	7.5	5.5	0.07
	Partner arthritis	31.7	42.7	<0.001
	Partner lung disease	6.8	5.1	0.08
	Partner CHD	11.8	6.0	<0.001
	Partner total conditions, mean (se)	2.0 (0.06)	1.9 (0.06)	0.1
	Partner total ADL difficulties, mean (se)	0.2 (0.02)	0.3 (0.03)	0.06
Household variables	Formal and informal care	10.7	10.9	0.8
	2 nd wealth quintile	21.6	21.6	
	Middle quintile	19.5	19.9	
	2 nd lowest quintile	20.6	18.5	
	Lowest wealth quintile	16.7	18.6	0.4
	Mortgage	18.8	19.7	
	Renting	8.9	8.8	0.9
	Household size, N (sd)	2.4 (0.03)	2.4 (0.03)	
	Below degree qualification	62.7	58.2	
	No qualification	19.2	14.7	<0.001
	Children living away	58.5	56.4	
Children living in household	22.9	32.8	0.01	

Notes: 2,843 couples with women with 1,430 women and 1,413 men. Data source: English Longitudinal Study of Ageing, COVID-19 sub-study wave 1; wave 9 (wealth quintiles, previously diagnosed conditions and ADL difficulties, tenure, limiting illness, education and children); weighted with COVID-19 sub-study longitudinal weight. Partner diagnosed conditions coded from all ELSA waves and new diagnosis in COVID-19 data. Significance tests: design-based F statistics and t-tests (continuous variables). Author's own calculations.

Table 9.10 Characteristics stratified by co-resident caregiving, COVID-19 wave 1

		No co-resident care during pandemic N=2,540 (89.3%)	Co-resident caregiver during pandemic N=303 (10.7%)	p value
Respondent variables	Poor sleep quality	38.7	48.6	0.009
	Age, mean (sd)	66.7 (0.28)	69.8 (0.83)	<0.001
	Women	46.7	57.8	0.003
	Non-limiting illness	21.6	22.8	
	Limiting illness	26.5	37.8	0.001
	Fair or poor SRH	18.5	32.6	<0.001
	3+ depressive symptoms	21.1	30.2	0.003
Partner health	Partner neurological	1.1	9.8	<0.001
	Partner cancer	6.0	10.7	0.003
	Partner heart condition	7.3	21.7	<0.001
	Partner lung disease	5.0	13.6	<0.001
	Partner arthritis	36.2	48.3	<0.001
	Partner total conditions	1.85 (0.04)	3.26 (0.18)	<0.001
	Partner total ADL diff (n)	0.16 (0.02)	1.09 (0.11)	<0.001
Household variables	Highest wealth quintile	21.7	19.4	
	2 nd wealth quintile	22.2	16.3	
	Middle quintile	19.7	19.6	
	2 nd lowest quintile	19.9	16.5	
	Lowest wealth quintile	16.5	28.2	0.002
	Owned outright	71.9	71.3	
	Mortgage	19.8	14.4	
	Renting	8.2	14.2	0.02
	Household size, mean	2.4 (0.02)	2.4 (0.06)	
	In paid work	29.5	10.9	0.001
	Employed but not	8.7	7.8	
	Other sources of care	7.5	39.1	<0.001
Below degree	60.5	59.0		

	No qualification	15.7	26.5	<0.001
	Children living away	57.4	57.5	
	Children living in	33.5	32.1	0.8
COVID-19- vulnerability and shielding	Personally shielded	21.0	37.3	<0.001
	Living in a hhd where one person shielded	17.7	30.1	
	Both shielded	8.6	23.1	<0.001
	Personally vulnerable to COVID-19	12.2	23.4	<0.001
	Living in a hhd where one person COVID-19 vulnerable	13.9	30.7	
	Both vulnerable	2.7	7.8	<0.001

Notes: 1,430 women and 1,413 men. Data source: ELSA, COVID-19 sub-study wave 1 and wave 9 (waves 1-8 for diagnosed conditions); weighted with COVID-19 sub-study longitudinal weight. Significance tests: design-based F statistics and t-tests (continuous variables). Author's own calculations.

9.5.2 Associations between co-resident caregiving, partner health and sleep quality

In this section, weighted logistic regressions were used to assess associations between co-resident caregiving, partner health and sleep quality in the early months of the COVID-19 pandemic. Results are presented for women (Table 9.11) and men (Table 9.12), adjusted for individual demographic, socioeconomic and health characteristics, household variables and partner health. Among women, results indicated co-resident care was associated with poor sleep quality in an unadjusted model, as found in Table 9.9 (Model 1). The association was explained however, by individual and household characteristics (Model 2) and did not substantively change when partner health conditions were added (Model 3). Considering partner health in Model 3, women who had a partner with arthritis had increased odds of poor sleep quality compared to non-caregivers (OR 1.48, CI 0.95: 1.07 – 2.05, Table 9.11 Model 3). No other partner health factor was associated with women's sleep quality. Among men, no associations were found between any of the key explanatory variables (co-resident caregiving or partner health factors) and sleep quality in any model (Table 9.12). As in all models in this thesis, consistent linkages were found with respondent health.

Table 9.11 Logistic regression of sleep quality by co-resident care and partner health, women only, COVID-19 wave 1

	Model 1 – caregiving only	Model 2 – respondent and household variables	Model 3 – partner health conditions
Co-resident care	1.56* (1.03 – 2.37)	1.46 (0.89 – 2.39)	1.40 (0.80 – 2.45)
Partner neurological			0.82 (0.42 – 1.89)
Partner cancer			1.29 (0.80 – 2.08)
Partner heart condition			1.05 (0.67 – 1.62)
Partner lung disease			1.48 (0.89 – 2.60)
Partner arthritis			1.48* (1.07 – 2.05)
Partner total conditions (n)			1.04 (0.93 – 1.15)
Partner total ADL diff (n)			0.99 (0.81 – 1.21)

Table 9.12 Logistic regression of sleep quality by co-resident care and partner health, men only, COVID-19 wave 1

	Model 1 – caregiving only	Model 2 – respondent and couple variables	Model 3 – partner health conditions
Co-resident care	1.29 (0.82 – 2.02)	1.00 (0.58 – 1.71)	0.96 (0.53 – 1.74)
Partner neurological			1.48 (0.55 – 3.97)
Partner cancer			1.54 (0.80 – 2.97)
Partner heart condition			1.26 (0.63 – 2.51)
Partner lung disease			1.44 (0.69 – 3.02)
Partner arthritis			1.30 (0.91 – 1.85)
Partner total conditions (n)			0.96 (0.85 – 1.08)
Partner total ADL diff (n)			0.96 (0.76 – 1.20)

Notes, Table 9.11 and 9.12: 1,430 women and 1,413 men. Reference groups: no co-resident care; no diagnosis. Model 2 and Model 3 adjusted for respondent variables: age, work status, limiting illness, SRH, depressive symptoms and household variables: wealth, tenure, household size, education, presence of children; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, COVID-19 sub-study wave 1 and waves 1-9; weighted. Author's own calculations.

9.6 CONCLUSION

The aim of this chapter was to investigate how co-resident caregiving, partner health and sleep were associated among cohabiting couples, addressing one aspect of the relationship context (partner health) in which caregiving and sleep occur. No evidence was found of a relationship between co-resident care provision and sleep disturbance for either women or men. In longitudinal gender-stratified analyses, co-resident care among men, but not women, was associated with an increased probability of sleep disturbance, similar to that found in chapter seven but this was accounted for with the addition of household variables. Poorer sleep quality among co-resident caregiving women was explained by individual characteristics in the cross-sectional COVID-19 analysis. In relation to partner health, in longitudinal analyses of women, a woman whose partner was diagnosed with a neurological disease had a 15% increased probability of sleep disturbance. No similar association was found for other partner health factors, and among men no associations were found with partner health. In cross-sectional analysis of COVID-19 data, no associations were found with partner health, except among women whose partner had arthritis, who were more likely to have poor sleep quality.

Situating the results within the existing literature, in studies of data collected prior to 2020, several population-based studies have found no association between co-resident care and dissatisfaction with sleep in New Zealand (Gibson et al., 2015), and short sleep duration in the United States (Blinka et al., 2022). Among studies of COVID-19 data, one investigated co-resident care, finding no association in a sample of only caregivers; sleep disturbance related to stressors associated with the pandemic (Beach et al., 2021). Higher levels of poor sleep quality were found in the ELSA COVID-19 data compared to earlier waves, consistent with other analyses (Falkingham et al., 2022; Wright et al., 2021). However, hypothesised poor sleep quality among co-resident caregivers due to greater pandemic-related stressors was not supported by the results.

With regards to studies including partner health, the results partially support studies finding care recipient health characteristics to be associated with worse caregiver sleep

(Liu et al., 2020; Secinti et al., 2022; von Kaenel et al., 2014). Previous research has predominantly investigated caregiving, partner health and sleep disturbance without comparison to non-caregivers. The results in this study therefore broaden the evidence base as no population-based longitudinal study has incorporated partner health in an investigation of caregiver sleep.

Counter to expectations, both the main survey and COVID-19 analyses found no link between co-resident care and worse sleep, once adjusted for personal characteristics. Adjustment for these characteristics included depressive symptoms, which may occur together with disturbed and poorer sleep. In addition, the longitudinal sample criteria required two waves of data from respondents, including partner health variables. The sample therefore excluded co-resident caregivers whose partner died prior to a second responding wave, when caregiving stressors are likely to increase and may cause sleep disturbance. In relation to the pandemic, the sample included a greater percentage of individuals in the higher wealth quintiles and owning their own property outright. The sample may have had access to supportive resources such as access to a garden or outside space that would lessen the impact of some movement restrictions. Although many caregivers lost opportunities for respite and support (Giebel et al., 2021), others indicated little change to already restricted lives, were able to connect via technology or new contact with neighbours or found benefits in a slower pace of life (Lightfoot et al., 2021; Sriram et al., 2021). Nevertheless, the research did not consider other health measures as outcomes such as depressive symptoms, loneliness or isolation and subjective wellbeing. Bergmann and Wagner (2021) found no association with trouble sleeping but problems with feeling sad, depressed and anxious, in their study of European non-resident parent caregivers.

In relation to the few links between partner health and a cohabiting spouse or partner's sleep, associations may be more proximal than can be identified by data collected four years apart. For instance, daily partner arthritis-related knee pain has been associated with the other partner's nightly sleep quality (Martire et al., 2013). Analysis of caregiving by disease type was not carried out due to low frequencies of care provision for some partner conditions and likely multimorbidity. This would however be of

interest. For instance, analysis of census data from Northern Ireland indicated individuals living with a person with dementia, whether caregivers or non-caregivers had a similar risk of poor mental health (Maguire et al., 2017). The authors suggested caregiving may be less important to mental health in challenging caregiving situations than the experience of living with an ill family member (2017). The results in this chapter contribute to literature on couple health, both in the context of, and irrespective of, caregiving. No evidence was found of sleep disturbance related to caregiving, expected either due to caregiver stress or to night-time provision of care (for instance, Arber & Venn, 2011). Instead, some, limited, evidence supported partner health, irrespective of caregiving status, as contributing to respondent sleep disturbance. This may be due to partner night-time restlessness due to medication side effects or symptoms such as pain (Hislop & Arber, 2006); or sleep disturbances experienced in response to the stress of having an ill partner, also known as a “family effect” in the caregiver health literature (Bobinac et al., 2010). As in the two previous chapters, individual health was most strongly associated with sleep disturbance and sleep quality. In the context of the COVID-19 pandemic, poor health may lead to clinical vulnerability to COVID-19 and the need to shield. These factors were more likely among co-resident caregivers in the ELSA data. Therefore, higher levels of poor sleep among female co-resident caregivers in unadjusted analysis may be related to their poorer physical and mental health, linked to sleep disturbance by physiology, or by increased stress caused by having health conditions that cause clinical vulnerability to COVID-19 (Di Gessa & Price, 2021).

Overall, the results of the chapter suggest that sleep disturbance in the period 2008 to 2017, and poor sleep quality during the COVID-19 pandemic, may be linked predominantly to changes in personal health. To a limited extent, certain partner health characteristics may be related to women’s sleep disturbance. The concluding chapter considers the findings across all empirical chapters, placing them within the context of the theoretical frameworks that guided the research and interpreting them through this lens. It addresses the strengths and limitations of the work and identifies possibilities for policy and practice and for future research.

Chapter ten - Conclusions

This thesis investigated relationships between caregiving and sleep disturbance among mid- and later life adults. The research addressed gaps in our understanding of how sleep disturbance may be associated with the characteristics of care, transitions and stability during caregiving and care duration. Differences according to the gender of the caregiver were a focus, and in the context of cohabiting couples, partner health. The caregiver stress process provided a theoretical framework for the research, complemented by insights from the sociology of sleep and stress process approaches to health among couples. This final chapter draws together results from the empirical research chapters, situating them within the existing literature and drawing out insights for theory, policy and practice and future research. Key findings are summarised in 10.1 and contributions to the development of the theoretical framework discussed in section 10.2. Recommendations for policy and practice follow in section 10.3. The strengths and limitations of the research are discussed in section 10.4 and ideas for further research and final remarks conclude the chapter and thesis in section 10.5.

10.1 KEY FINDINGS

This section considers the findings in the light of previous research and the theoretical frameworks guiding the research, to interpret the key results. Overall, investigations within the empirical chapters indicated some, modest, longitudinal associations between caregiving and sleep disturbance, differing by gender. Results were inconsistent across statistical models and all associations between caregiving and sleep disturbance were weak and indicated small increases in the probability of sleep disturbance. Based on prior research and the theoretical frameworks, sleep disturbance was expected to be associated with aspects of care provision more likely to be perceived as stressful. Partner health was hypothesised as linked to respondent sleep, and all associations were expected to be stronger among women than men. Partial support was found for hypothesised relationships between longer hours of care provision, and spouse care, and sleep disturbance (research question one). Contrary to expectations, men but not women caregiving for 20 hours or more per week, and for a

caregiving for a spouse, had an increased probability of sleep disturbance. For men, the findings were broadly in line with hypothesised relationships, although associations were weak. Among women, depressive symptoms explained the association between longer hours and sleep disturbance, and loss of a spouse was associated with sleep disturbance, rather than provision of spouse care. As anticipated, no association was found with lower intensity care, or other care relationships. In relation to transitions and stability in care provision (research questions two and three) evidence did not support hypothesised relationships. Sleep disturbance was expected on starting and continuing to provide care, reducing with cessation of care. Contrary to expectations, in main analyses, ceasing care was linked to an increased probability of sleep disturbance among women and no associations were found among men. Only in sensitivity analysis of imputed data was sleep disturbance linked to women who started to provide care. The final part of chapter eight, investigating care duration and sleep disturbance hypothesised a relationship between caregiving for a longer duration and sleep disturbance (research question four). Partial support was found for this hypothesis, among women but not men. Finally, in chapter nine, contrary to expectations, none of the results indicated a relationship between co-resident care provision and sleep disturbance among women or men, including during the early months of COVID-19 pandemic (research questions five and six). Among women, limited evidence indicated partner health (diagnosis with a neurological disorder and having asthma) was related to respondent sleep disturbance. This aligned with explanations derived from the sociology of sleep and stress approaches to health among couples that note that partner ill health may disturb respondent sleep through night-time symptoms or respondent distress. However, no other evidence indicated partner health was important for sleep disturbance among women or men. Overall, as found in previous studies, women had greater sleep disturbance than men, measured by the three single sleep questions contributing to sleep disturbance in chapter six. In all analyses, changes in respondent health, such as pain, limiting long-term illness, self-rated health, and particularly depressive symptoms, had the strongest relationships with sleep disturbance, in line with epidemiological evidence.

In more detail, of the characteristics of care modelled in chapter seven, caregiving for 20 or more hours per week and spouse care increased the probability of reporting sleep disturbance among men by 7% in complete case analysis. Among women, only care of 20 or more hours was associated with sleep disturbance and this was explained by depressive symptoms in complete case analysis. The results provide some support for previous population-based research findings linking longer caregiving hours to disturbed sleep, among working adults (Sacco et al., 2018), all adults (Arber & Meadows, 2011b; Liu et al., 2020; Secinti et al., 2022), and adults aged 65 and over (Maun et al., 2020). Spouse care has also been linked with symptoms of insomnia, in combination with high depressive symptoms, in a small cross-sectional study (Kochar et al., 2007), few other studies specifically analysing relationship to the care recipient. The results provide partial support for a stress process explanation among men, where longer hours of care and spouse care are hypothesised to be more stressful. The caregiver stress process framework asserts that stressors such as longer hours of care are likely to alter the balance within a relationship between caregiving and other life domains (Pearlin et al., 1990). Providing longer hours of care may take up time ordinarily used for other activities and can lead to changes in work, family and social life which may be perceived or experienced as stressful (Bowes, Dawson, & Ashworth, 2020; Carmichael & Ercolani, 2016). Shorter hours of care or care for relatives other than a spouse may be able to fit around other activities and provide more benefits to the caregiver, such as increasing appreciation of life (Bom & Stöckel, 2021; Rafnsson et al., 2017; Raschick & Ingersoll-Dayton, 2004). That depressive symptoms explained associations between caregiving of 20 hours per week and sleep disturbance in complete case models among women may be indicative of the close relationship between sleep and depressive symptoms (Fang et al., 2019). Conflicting results have been found among studies including both sleep and mental health. For instance, negative affect was found to fully mediate caregiving-sleep quality associations in relation to care for a person with dementia (Brummett et al., 2006), while depressive symptoms partially mediated the relationship between sleep quality and quality of life in a separate study (Cupidi et al., 2012). As sleep data points in the analyses were four years apart, untangling the direction of association between sleep disturbance and depressive symptoms in relation to caregiving is challenging. Indeed, complex associations have been found using ELSA data in analysis of the epidemiological

relationships between sleep disturbance and depressive symptoms (Poole & Jackowska, 2018). Among longitudinal studies adjusting for depressive symptoms, those focusing on samples of older adults and dementia care, found depressive symptoms rather than care provision was associated with sleep disturbance (Rowe et al., 2008; von Kaenel et al., 2012). In contrast, larger scale cross-sectional studies of all adults have found associations remained with adjustment for depressive symptoms (Blinka et al., 2022; Koyanagi et al., 2018). The approach taken in chapters seven and eight, where depressive symptoms was added in a separate model may be the most appropriate strategy, an approach taken by one study of caregiver quality of life (Sacco et al., 2022).

Transitions and stability in care provision and care duration were modelled in chapter eight. Hypothesised relationships between transitions/stability and sleep were not found at all among men and associations contrary to expectations were found among women. Women starting to provide care (imputed data) and ceasing caregiving (complete cases) but not care over two consecutive waves, was associated with sleep disturbance. In imputed data, widowhood rather than care cessation, was associated with sleep disturbance. Analysis of change in sleep disturbance indicated female caregivers had a higher relative risk of sleep disturbance in both the wave preceding and after ceasing care. The only result in line with expectations, caregiving for two or more waves, but not for one wave only, was associated with sleep disturbance among women. In previous studies, starting to provide care (Hajek & Koenig, 2022; van de Straat et al., 2021) and ceasing care (van de Straat et al., 2021) have been associated with poorer sleep in mid- and late life adults, and ceasing care among caregivers of people with Alzheimer's disease whose spouse died (von Kaenel et al., 2012). In relation to care duration, the results were consistent with studies linking longer care duration to short (Liu et al., 2020) and disturbed sleep among samples of caregivers (Simon et al., 2019). End of life care may be a period of intense emotion and demanding care provision, and individuals may begin to grieve, anticipating widowhood (Breen, L. J. et al., 2018). The period after ceasing care due to bereavement and widowhood may involve difficult changes to social life and financial circumstances. Sleep disturbance may also be related to ceding care to formal home care workers, or a nursing or residential home. This can be stressful, and caregivers may feel guilt or discomfort in

making a change (Gaugler, Mittelman, Hepburn, & Newcomer, 2010). As analysis of change in sleep disturbance also indicated the presence of sleep disturbance prior to ceasing care, the results may also include some reverse causality, as poor sleep due to caregiving at night has been identified as a reason for nursing home admission (Afram et al., 2014). Previous analysis of ELSA data also found depressive symptoms increased when care to a spouse or child ceased (Rafnsson et al., 2017). This may be related to bereavement as discussed above and may also point to characteristics of care cessation in the English context. For instance, the limited availability and high cost of nursing home placements could increase worry and financial pressure (Burchardt, Jones, & Obolenskaya, 2018). Considering associations with longer care duration, prolonged care may increase in intensity and necessitate changes in work, social life and daily rhythms which may impinge on sleep at night (Arber & Venn, 2011). Caregivers can be reluctant to use community or home-based support, which may also increase strain over time (Gaugler, Kane, Kane, Clay, & Newcomer, 2005). Chronic conditions causing care recipients to be restless at night or neurological conditions that can disrupt circadian rhythms often involve care for longer duration and may provide an additional explanation for this association (Kim & Schulz, 2008; Pistacchi et al., 2014; Zahed et al., 2021). However, as analyses were not able to include measurement of sleep disturbance prior to the start of care provision for all caregivers, the association found may be due to factors that predict the provision of care of longer duration and are also associated with sleep disturbance. One such potential factor is socioeconomic status, as analysis indicated a negative relationship between the relative risk of providing care for two or more waves and wealth.

Possible influences of co-resident care and partner health on sleep disturbance among cohabiting couples were explored in chapter nine. Contrary to expectations, no associations were found between co-resident caregiving and sleep disturbance in adjusted analyses of ELSA main waves, or sleep quality in COVID-19 data among women or men. Mixed results have been found of previous studies of location of care, several finding other factors and not care location, were related to sleep disturbance (Blinka et al., 2022; Gibson et al., 2015). In relation to partner health, few partner health conditions were associated with respondent sleep disturbance, none among men.

Among women, a woman whose partner was diagnosed with neurological disease had a small increased probability of sleep disturbance in longitudinal analyses. Cross-sectional analysis of COVID-19 data indicated an association among women who had a partner with arthritis and poor sleep quality. Partner health results contribute to the caregiver sleep literature where a care recipient's behavioural difficulties or severity of condition has sometimes been linked to worse caregiver sleep (for instance, Happe et al., 2002; Leggett et al., 2018; Liu et al., 2020). The results provide limited support for the relationships hypothesised, however, they expand knowledge by carrying out the analysis within the wider context of couple health, by analysing both caregiving and non-caregiving cohabiting individuals. The results align with a stress approach to health among couples as well as the sociology of sleep, where partner health could be related to sleep disturbance through physical disturbance at night or through distress at having an ill partner (Hislop & Arber, 2006; Thomeer, 2016). For instance, a woman whose partner has been diagnosed with a neurological disease may experience disrupted sleep due to worry about future difficulties and changes to life, frustration at limited support and information, or grief (Lee, Puga, Pickering, Masoud, & White, 2019). In relation to arthritis, a partner in chronic pain may reduce or cease their involvement in paid work and household tasks, increasing the burden on their spouse with potential consequences for sleep (Suso-Ribera, Yakobov, Carriere, & Garcia-Palacios, 2020). That a partner's health condition or new diagnosis may affect a woman's, but not a man's sleep is consistent with sociological perspectives on the enactment of gendered social roles (Hislop & Arber, 2003b; Meadows et al., 2008). However, it is important to note the low frequency of transitions available for analysis, particularly among men, though results from imputed data were consistent with those from complete cases.

Gender differences were hypothesised for all research questions: stronger associations were expected among women than men. Although women had higher levels of sleep disturbance in general than men, measured by the individual sleep questions, see chapter six, there were few gender differences in associations between caregiving and sleep. Differences that were identified were sometimes contrary to theoretical expectations, for instance, sleep disturbance related to spouse care among men but not women. Several previous studies have found male spouse caregivers (Mills et al., 2009),

working caregivers (Sacco et al., 2018) and mid- to late-life caregivers (Hajek & Koenig, 2022) were more likely to have sleep disturbance, with no differences among women. Men may face difficulties in adjusting to managing unfamiliar care tasks or household responsibilities (Calasanti & Bowen, 2006). Further, the size of their social support network tends to decrease in older age, with married men tending to receive most support from their spouses, posing a potential additional strain which may lead to sleep disturbance when their spouse becomes ill (Fee, McIlpatrick, & Ryan, 2021; Gurung, Taylor, & Seeman, 2003; McLaughlin, Vagenas, Pachana, Begum, & Dobson, 2010). That a similar association with sleep disturbance was not found among women and for co-resident care was surprising as spouse care among women has been linked to worse psychological health (Bom et al., 2019). That becoming a widow was associated with sleep disturbance in chapter seven and in sensitivity analysis using imputed data in chapter eight may offer an explanation for the differences found among women and men in relation to spouse care. For women, the loss of a life partner, more so than the provision of care to the partner, may affect sleep. Indeed, care for a spouse may be a source of comfort (Freedman et al., 2014) beneficial for sleep when providing a sense of purpose and closeness (Chen, 2019). In contrast, bereavement may bring sleep disturbance due to grief, worries about finances and safety, as well as the loss of well-known sleep routines developed and sustained with the lost spouse (Corey & McCurry, 2018; Stahl & Schulz, 2014; Walker et al., 2012).

Overall, the results imply weak linkages between caregiving and sleep disturbance among men and women, with some gender differences. Among women, the end of care provision and the transition to widowhood were linked to sleep disturbance and partner health, particularly the diagnosis of neurological disease and a partner with arthritis, increased women's sleep disturbance, irrespective of care provision. Among men, longer hours of care and spouse care increased the probability of sleep disturbance and though no other associations were found, data limitations may be a factor. Equivocal support was found for several of the hypothesised relationships based on the caregiver stress process framework and some limited evidence was found for the importance of partner health to respondent sleep, expected based on sociology of sleep and stress approaches in couples. The importance of relationship transitions was

suggested by the association of widowhood with sleep disturbance. Individual physical and mental health were strongly and consistently associated with sleep disturbance. The next section considers how the research has contributed to theory development.

10.2 CONTRIBUTION TO THEORY

The conceptual framework for this thesis was developed to provide guidance relevant to investigating how caregiving relates to sleep disturbance among mid- and late life adults. It combined insights from stress process approaches applied to caregivers, and health among couples, with understandings from the sociology of sleep. Use of the caregiver stress process is common in caregiver sleep research. Less common is the combination of insights from the sociology of sleep and stress process models of health among couples, to enhance understanding of the ways in which sleep may be influenced by gendered social roles, and by partner health and relationship transitions among couples (Hislop & Arber, 2006). This section considers how the research results contribute to the theoretical frameworks underpinning the study, starting with the stress process and then the sociology of sleep.

Three domains of the caregiver stress process framework were the focus of this research: background characteristics, primary stressors, and outcomes. The research contributed to knowledge of the dynamic way in which caregiving is associated with sleep disturbance, through the investigation of changes in caregiving and differing patterns of association over a caregiving episode. This investigation of change over time aligns directly with the stress process, deliberately named, as stress was conceived as arising over time and fluctuating with changing circumstances (Pearlin et al., 1990). Much of the existing caregiver sleep research is cross-sectional and necessarily contributes evidence of association with static characteristics and circumstances. However, associations found were weak and inconsistent between care provision and sleep disturbance. Limited evidence supported the hypotheses drawn from the stress process framework. This includes differences by gender. Possible ordering of outcomes of caregiving was suggested in the original stress process framework. This is of relevance in this research, as depressive symptoms accounted for higher probability of

sleep disturbance among women providing longer caregiving hours in some analyses. Depressive symptoms may be both a confounder of care provision and sleep disturbance, distress having been found to predate caregiving (Hirst, 2005) and depressive symptoms a known risk factor for sleep disturbance (Fang et al., 2019). However, sleep disturbance may also mediate the relationship between care provision and depressive symptoms or be an early symptom of developing depression (Fang et al., 2019). Sleep disturbance and depressive symptoms are often intertwined in the older population, where levels of co-morbidity are high and previous evidence in caregiver sleep studies and more widely has indicated complex and bidirectional patterns (Poole & Jackowska, 2018). In this study, sleep data points were four years apart and analyses did not attempt to distinguish the ordering of changes in sleep and depressive symptoms, or whether caregivers with depressive symptoms were more likely to have sleep disturbance. It may be that sleep disturbance is a less common expression of caregiver stress or occurs in circumstances likely to also increase depressive symptoms.

In relation to caregiving, partner health and sleep disturbance among couples, combining stress process and sociology of sleep perspectives enabled the partial differentiation of possible mechanisms influencing sleep disturbance. Associations with caregiving could be delineated from those relating to having an ill family member (due to distress or partner night-time symptoms or medication side effects). The conceptual model combined knowledge of health among couples; so called “caregiver effects” and “family effects” in the wider caregiver health literature; and insights from the sociology of sleep linking sleep to significant role transitions, gendered social roles and changes in health with age (Hislop & Arber, 2006). The combined theoretical model adds to recent research which has contributed to new uses of the stress process and added to the theoretical basis for the sociology of sleep. For instance, recent research has combined stress process and sociology of sleep approaches in the study of couples’ sleep and psychological distress (Chen, 2018); and life course, role theory and sociology of sleep in investigations of sleep in mid- to late life, including caregiving transitions (van de Straat et al., 2021).

Analyses among couples indicated only a few associations between partner health and respondent sleep. Overall, there was limited evidence to support sociology of sleep and stress process views of connections between partner health and sleep among couples. Nevertheless, some evidence among women supported the hypothesis that deteriorating (neurological disease) and poor (arthritis) partner health may influence respondent sleep. The results more generally supported a sociological view of sleep as “a mirror of everyday life” (Dzaja et al., 2005, p69), influenced by individual physiological and relational, as well as other, factors (Hislop & Arber, 2006). Individual physiology in the form of changes in individual health were found to be the strongest correlates of sleep disturbance. However, associations were also found related to roles, responsibilities, and transitions. For instance, interdependent relationships, important to care and sleep, were indicated by links between change in partner health and sleep disturbance among women in chapter nine. Further, the transition to widowhood was important for women’s sleep in chapters seven and eight. Finally, that male spouse caregivers had a higher probability of sleep disturbance but not women, may indicate changing gender roles with the changing circumstances of older age.

10.3 POLICY AND PRACTICE IMPLICATIONS

Although associations were weak, the results in the thesis provide some evidence of specific characteristics of caregiving, transitions, and duration where sleep disturbance may be more likely. Possible practice implications are discussed first, in relation to opportunities for identification of sleep difficulties and support. Second, stemming from the limitations of the data used in this thesis, see section 10.4, the availability of sleep data and of caregiving sub-groups within population-based and social care datasets is discussed. With relevance to practice, the results in chapters seven and eight indicated sleep disturbances were more likely among men providing spouse care, and caregiving for longer hours per week (20 hours or more). Sleep disturbance among women was also more likely to occur towards the end of care and following the cessation of care. Additionally, the transition to widowhood among women was associated with sleep disturbance, and widowed women may be an important but less visible group who may benefit from support (Lancel et al., 2020). A psychosocial screening tool for use by GPs or other practitioners has been recommended by some, to be incorporated into

consultations with identified caregivers (Corey & McCurry, 2018) or in discussions with bereaved individuals (Lancel et al., 2020). Routine screening for sleep problems by GPs and nurses has been advocated more widely (Royal Society for Public Health & University of Oxford, 2016) and could be a means of identifying and addressing sleep disturbances among caregivers and widowed individuals. Indeed, opportunities for identifying needs and supporting caregivers is an important thrust of recent guidance for health and social care professionals (National Institute for Health and Care Excellence, 2020), as well as guidance for GP practices aiming to be caregiver friendly (NHS England and NHS Improvement, 2019). In relation to men, older men may be less likely to acknowledge their caregiving status or to seek help from friends or professionals (Greenwood & Smith, 2015; Milligan & Morbey, 2016). Further, men have been found to downplay their sleep difficulties, be less aware of practices promoting sleep and less inclined to try self-help measures (Sidani, Guruge, Fox, & Collins, 2019; Venn, Meadows, & Arber, 2013). Other methods of offering support could include consistent signposting of online information on Local Authority and local service provider websites (Willis & Lloyd, 2021), linking to sleep advice for caregivers and more generally, such as those on Carers UK and The Sleep Charity websites²⁷. Local caregiving organisations could add discussion and advice on sleep into their group-based support offer. Opportunities offered by social prescribing, improved information access and new approaches to caregiver support are identified within the social care white paper, some affording additional funding (Carers UK, 2021a; Department of Health and Social Care, 2021). However, results from analyses in this thesis indicated only weak and inconsistent associations between care provision and sleep disturbance. Policy initiatives to identify and support caregivers with sleep disturbance may best be carried out as part of wider initiatives for all individuals (Royal Society for Public Health & University of Oxford, 2016), rather than divert scarce caregiver-focused resources.

In addition to practice-based implications, a secondary implication arising from the thesis relates to the paucity of available sleep data and availability of data on caregiving sub-groups, see section 10.4. Future research would benefit from UK data sources containing greater numbers of sub-groups of caregivers and more frequent

²⁷ [Getting enough sleep - Carers UK](#) and [Home - The Sleep Charity](#)

measurement of sleep. Of the nationally representative cross-sectional and longitudinal sources of social care data in the UK (King & Wittenberg, 2015), few incorporate regular measures of sleep, and none measure sleep at all waves. Inclusion of questions on sleep at every wave in large surveys would allow closer modelling of changes in sleep with changes in care and be of benefit for wider analyses of sleep. The Health and Retirement Study in the US is an example of such data, as it has incorporated sleep questions similar to the Jenkins sleep problems scale at every wave since 2004 and single sleep questions in some earlier waves (Health and Retirement Study, 2020). Further, sub-groups of caregivers can be relatively few, particularly in longitudinal samples, resulting in a loss of power in analyses. Academics and policy makers recognise the need for more comprehensive data on social care, covering the full range of individuals and settings where paid and unpaid care is received and provided (Carers UK & CIRCLE, 2018). Indeed, the social care white paper outlines commitments for improving adult social care data, including caregiving (Department of Health and Social Care, 2021). Datasets including a larger proportion of caregivers would enable more robust analysis of caregiver sub-groups, critical as wider caregiver health studies have found results differ based on the characteristics of caregivers and their circumstances (Bom et al., 2019). Administrative sources of data on caregivers are available (Hussein, 2011), holding larger sample sizes of specific groups. For instance, data is collected annually on caregivers supported by Councils with Adult Social Services responsibilities, the Personal Social Service Survey of Adult Carers in England (PSS SACE) and includes information on disturbed sleep²⁸. However, the survey was designed primarily to capture information about Council-supported caregivers and evidence of service outcomes and does not lend itself to research questions on the wider population of caregivers. Revision of the collection of this data with the aim of making it representative of adult social care (Department of Health and Social Care, 2021) may offer new opportunities to analyse all caregivers, not only those in receipt of Local Authority support. New data linkage between the Census and administrative health datasets also offers exciting future possibilities for some types of analysis (Bennett, 2021 presentation at Sustainable Care conference). However, as noted above,

²⁸ Respondents are asked to identify how their health has been affected by caring. Disturbed sleep was the second most common response, 64% in the 2016/17 survey and 66% in the 2018/19 survey (NHS Digital, 2017; NHS Digital, 2019).

information on sleep is not routinely included in health screening in the UK (Royal Society for Public Health & University of Oxford, 2016).

10.4 STUDY STRENGTHS AND LIMITATIONS

In this section, strengths and then limitations of the research are discussed. Research strengths lie in the use of high-quality longitudinal data to address aspects of caregiving and sleep disturbance previous longitudinal studies have not covered, including the relationship of care and incorporating measures of partner health. The literature review provides the first synthesis of the available population-based evidence on caregiver sleep. Finally, analysis included advanced panel methods to address time-constant sources of observed and unobserved difference between individuals, and model change, methods used in only a handful of caregiver sleep studies.

The study used a high-quality longitudinal source of nationally representative data, ELSA, which benefits from management processes designed to maximise responses and minimise attrition among the focus population, adults aged 50 and over (NatCen Social Research, 2018). Historically, caregiver sleep studies have focused on groups of caregivers of people with conditions linked to symptoms of sleep disturbance, such as dementia and various advanced cancers (Byun et al., 2016). Studies often lacked a group of non-caregiver controls and implications may not be relevant to other types of caregiving from this type of research design, though they provide evidence for supporting caregivers of patient groups. In recent years, a handful of longitudinal population-based studies have provided evidence that can be inferred at a national level, encompassing UK, mainland European and Scandinavian contexts. This thesis extends research in the English context, using advanced methods, a wider range of covariates and caregiving characteristics, filling gaps in the available evidence. Further, it explored data collected during a time of financial pressure on the social care system, providing evidence relevant to policy makers and practitioners determining how best to spend scarce caregiver support resources to maintain caregiver wellbeing. Second, many of the population-based studies on caregiver sleep have been published in the last five years and no published review has synthesised this evidence. Previous reviews

often focused on specific caregiver types and smaller scale studies or were written before most population-based studies were published, see section 2.5.1. Chapter three therefore provides a unique overview of the population-based evidence.

Third, this study addressed a wide range of caregiving characteristics and transitions/stability during care provision, as well as the importance of partner health among cohabiting couples, considering gender differences. Several caregiver health studies have sought to analyse a range of different measures of caregiving and their potential consequences within the same study (Bom & Stöckel, 2021; Sacco et al., 2022). Population-based caregiver sleep studies by contrast have until recently focused on fewer characteristics of caregiving and on transitions, predominantly carrying out cross-sectional research. In this light, to my knowledge this is the first longitudinal, population-based exploration of care relationship or care duration and sleep disturbance, and how partner health and co-resident caregiving may relate to sleep disturbance in cohabiting individuals. The thesis was guided by a conceptual framework, combining strengths and insights relating to caregiving, health among couples and the sociology of sleep. It focused on characteristics of caregiving likely to be experienced or perceived as stressful and sought to draw out differences by gender and the shared nature of both caregiving and sleep. In the context of cohabitation caregiving and sleep were considered as embedded within relationships (Hislop & Arber, 2006) and influenced by the health characteristics of those relationships (Kiecolt-Glaser & Wilson, 2017). Fourth, the use of advanced statistical methods allowed changes within individuals to be assessed, addressing the issues of time-constant sources of selection bias and omitted important variables that may influence both caregiving and sleep disturbance, such as personality characteristics. Only in more recent caregiver sleep studies have advanced statistical methods been adopted and studies set within a population-based context.

The study's limitations relate to variable measurement, including the measurement of sleep disturbance; the consequences of limited availability of sleep data and low frequency of some caregiver sub-groups; the use of fixed effects models in the context of the data available; and several important but omitted variables. First, although the

research used the validated, multi-question Jenkins sleep problems scale (Jenkins et al., 1988) to form the sleep measure for the study, the variable had several shortcomings. First, is the lack of a tested cut-off point for the Jenkins sleep problems scale (Jenkins et al., 1988). As a result, studies have used different cut-off points for high sleep disturbance (Di Gessa et al., 2017; Jackowska et al., 2013; Miller, M. A. et al., 2014) or the continuous measure (Jackowska & Steptoe, 2015; Jackowska & Poole, 2017; Poole & Jackowska, 2018). In chapters seven and eight, sensitivity to measurement level was addressed by regressing the continuous measure of sleep disturbance in sensitivity analyses, as well as the binary measure used in main analyses, as advised by other authors (Chen, 2019). Both continuous and binary measurements have limitations. The continuous measurement gives an indication of changes in severity of sleep disturbance though interpretation is challenging given the ordinal rather than scale nature of the response options on which it is based. The binary variable results may be difficult to compare to other studies as the definition of the cut-off point differs dependent on the study data rather than on practically or clinically meaningful differences (Bennette & Vickers, 2012). In this study, the method of calculating the cut-off point led to lower prevalence of sleep disturbance among women than men, though individual problems were more common among women. Some women who perceived their sleep to be disturbed may have been coded as low sleep disturbance as a result. Subjective sleep measures, recalled over the previous month, may also be subject to recall bias (Kotronoulas et al., 2013). Comparison between objective measures of sleep disturbance, such as wake after sleep onset, and individual perceptions was not possible as objective measures of sleep are not yet available in the ELSA sample. Finally, no information was available to indicate the reasons for sleep disturbance, though these were assumed in the conceptual framework. For instance, sleep disturbance associated with care provision was assumed to be primarily due to caregiving-related stress or, in more limited circumstances, to night-time provision of care. However, direct measures of caregiver stress and night-time provision of care were not available. The ELSA dataset does not contain a measure of perceived stress, though C-Reactive Protein, a measure of chronic inflammation and one marker of physiological stress, was available, collected during nurse visits (Gruenewald, Lee, & The Stress Network, 2017). Inclusion of C-Reactive Protein was considered early in analyses but would have resulted in a large loss of cases in analyses already constrained by the size of caregiving sub-groups.

In chapter nine, hypothesised links between partner health and respondent sleep disturbance, due to worry or to partner night-time restlessness could not be directly tested.

A second set of limitations relates to the consequences of the limited availability of sleep questions. Although care provision was measured at each ELSA wave, a gap of two years, sleep questions were included in every other wave. Consequences of this limitation include possible bias in the samples available for analysis and an inability to capture changes in sleep of shorter duration. Sample selection required participants to have two complete waves of data four years apart. Individuals in the most challenging circumstances, or caregivers who were most challenged by their caregiving experiences, may have been less likely to continue to respond to the survey, or drop out for a period of time. Robust processes for respondent follow-up are a strength of the ELSA survey, which has high initial and subsequent response rates (NatCen Social Research, 2020a). Nevertheless, attrition in ELSA is higher among individuals of lower socioeconomic status, as in other longitudinal studies (Steptoe et al., 2013). In one analysis, lower education was found to predict attrition in ELSA, with no additional attrition based on health once mortality was accounted for (Banks et al., 2011). Samples selected for longitudinal and couple analyses in chapters seven, eight and nine of this thesis were less likely to include individuals in the lowest wealth quintiles and in poorer health than the dropped cases (see chapter six, section 6.5). Therefore, sample attrition and the requirements of sample selection may have led to bias in the results, in this case, potentially underestimating the associations observed (de Zwart et al., 2017). Sleep variable availability also limited the changes in sleep that could be observed. Fluctuations in sleep are common across a 7-day period (Marini et al., 2020), yet sleep characteristics have a high degree of stability across multiple years (Fatima et al., 2020). This research was not able to investigate changes in sleep disturbance of less than four years, for instance, periodic disturbed sleep linked with caregiving for someone with an unpredictable illness (Bianchera & Arber, 2007), across the course of 3-6 months of cancer treatment (Kotronoulas et al., 2016) or accompanying the final stages of care for someone with terminal illness (Bianchera & Arber, 2007). In addition, in analyses in chapter eight, although caregiving transitions and stability were measured across two

consecutive waves, two years apart, sleep and other covariates were measured four years apart. Other life changes occurring over a shorter period may have confounded the associations found with sleep disturbance. The Health and Retirement Study has similar sleep questions to those in ELSA at every survey wave since 2004, collected two years apart (Health and Retirement Study, 2020). However, HRS was discounted as the United States care context is very different to the UK. The UK Household Longitudinal Study was also considered, however, the study also measured sleep only every other wave and there was a high level of missing sleep data in the first wave of the study, affecting sample size, see Methodology section 5.2.2.

Limitations relating to the caregiving questions available had consequences for the size of caregiver sub-groups in analyses and the accuracy of modelling changes in care and care duration. Consistent measurement of variables over time is a requirement for fixed effects models (Allison, 2009b). Prior to wave six, detailed questions on “looking after someone” in the last week were only asked to individuals who had responded yes to providing care for someone in the last month (NatCen Social Research, 2014). To maintain a consistent approach to the coding of caregivers across waves, only those individuals answering yes to providing care in the last month and looking after someone in the last week were coded as caregivers (Rutherford & Bu, 2018). This approach reduced the number of individuals coded as caregivers. It was more likely to exclude men, spouse caregivers and those providing low hours of care per week, who may not have identified themselves as providing care, though might otherwise have indicated they looked after someone (Rutherford & Bu, 2018). Other studies have adopted the same approach, though analysis focused on all caregivers rather than caregiver sub-groups (Yuan & Grün, 2020). Data availability also precluded capturing caregiving lasting less than four years in chapter seven and nine (due to availability of sleep data as detailed above), and less than two years in chapter eight (measuring transitions and stability). In addition, no prior information was available on care history, of relevance to the measurement of care duration (Fast et al., 2021). These types of limitation relating to variable availability and frequency of surveys are common limitations of nationally representative data, due to the feasibility of surveying at more regular intervals and the limit to the number of questions that can be included.

A fourth set of limitations relate to the consequences of analysing caregiver sub-groups using fixed effects models with the data availability limitations already presented. Segmenting caregivers by hours, relationship, location, and transitions, in addition to gender stratification was guided by theory and gaps in the empirical literature. However, these choices created some small categories, particularly among men. The decision to analyse caregiving transitions and duration for care of 20 or more hours was made to focus on care provision more likely to be stressful, as lower hours of care have been linked to neutral or positive health benefits. However, there were few observations of continued care over two consecutive waves in the data, particularly among men. Use of fixed effects models compounded the issue of low frequency in these variables as only cases where there is change in a variable over time contribute to coefficient estimates, due to time-demeaning (Andres et al., 2013; Collischon & Eberl, 2020). Other studies of caregiver health have also been limited by low frequency of caregiving sub-groups and transitions (Kaufman et al., 2019; van den Broek & Grundy, 2018b). The result may be low statistical power and reduced ability to detect small associations, in addition to associations arising through noise in the data (Kaufman et al., 2019; van den Broek & Grundy, 2018b). Fixed effects models were used due to violation in the assumption of independence between unobserved and observed variables in random effects models (Allison, 2009b). However, sensitivity analysis using imputed datasets increased sample sizes, providing mostly consistent results, except in the caregiving transition analysis, Appendix Table E6, and noted above.

Finally, in chapter nine, partner health variables included in analyses were those physical health conditions found to be associated with sleep disturbance in adjusted analyses in studies reviewed in Literature review section 3.4. Inclusion of partner body mass, a measure of obesity, would have resulted in a significant reduction in sample size. This is due to weight being measured in the nurse visit until wave 8 and height measured only in nurse waves 4 and 6 (NatGen Social Research, 2020b). Partner diagnosis with diabetes was not included in analyses as no studies found an association between the condition and sleep disturbance in adjusted analyses (Foley et al., 2004; Koyanagi et al., 2014; Poole & Jackowska, 2018). However, a recent cross-sectional

population-based study found higher odds of short sleep among caregivers of a person with diabetes (as well as caregivers of people with other disease types included in chapter nine) (Secinti et al., 2022). Inclusion of partners with diabetes may be important to include in future research. Finally, the caregiver stress process framework envisages a greater array of factors affect the experience and perception of caregiving as stressful, with health and wellbeing consequences. The study was not able to include measures such as perceived overload, as these are rarely included in population-based studies.

10.5 FUTURE RESEARCH AND CONCLUSION

This final section considers possible future research opportunities and draws the thesis to a close. Research possibilities include further investigation of caregivers during and after the COVID-19 pandemic, and transition to and after widowhood. First, results in chapter nine found several links between partner health and a woman's poor sleep quality and sleep disturbance. Although care provision is by nature a shared experience there are relatively few population-based studies that include partner measures in the study of caregiving. As the population of older spouses increases, research addressing the interplay of health and wellbeing within couples is highly relevant. Research could address how partner health is associated with other measures of respondent wellbeing, such as quality of life and life satisfaction. This could include both the provision and receipt of unpaid and other sources of care (Floridi et al., 2021; Han et al., 2021). The second half of chapter nine included a cross-sectional analysis of data from June and July of 2020, in the early months of the COVID-19 pandemic. Descriptive statistics highlighted co-resident caregivers were significantly more likely themselves to have a limiting illness, poor self-rated health and high depressive symptoms, were more likely to be personally vulnerable to COVID-19 and to have shielded. In recent pandemic-related research, co-resident caregiver mental health was found to worsen from 2019 to April 2020 and to continue to be worse for some groups between April and July 2020 (Whitley et al., 2021). A second wave of ELSA COVID-19 data is now available and as further ELSA waves become available, changes in caregiver mental and physical health associated with previous shielding behaviour and care provision, as well as socioeconomic status, may be important to investigate.

Finally, evidence from the thesis indicated becoming a widow was consistently associated with sleep disturbance in chapter seven and sleep disturbance was more likely towards the end of caregiving, on ceasing care, and after widowhood, among women in chapter eight. Grief following bereavement can include sleep disturbances as one of a range of psychological and physiological responses which may last up to six months following bereavement, in an uncomplicated grief response (Shear, 2015). In the Literature review, section 3.5.4, Gerlich and Wolbring (2021) found increased odds of dissatisfaction with sleep among bereaved caregivers and the raised odds continued for up to three years following widowhood. However, although the analysis used fixed effects models, age was the only covariate included. With the transition to widowhood many other circumstances would be expected to change, which may include finances, social support, housing and loneliness. Several reviews have indicated the need for prospective studies to investigate the transition to and following widowhood and sleep disturbance (Stahl & Schulz, 2014). The most recent found 24 studies undertaking longitudinal analysis of bereavement and sleep disturbance (Lancel et al., 2020). However, only two that were population-based and included comparison to those who were not bereaved (Erlangsen et al., 2017; Milic et al., 2019). Research could be carried out addressing the years following widowhood, in the presence or absence of prior care provision, taking advantage of HRS data which includes month and year of spouse death and sleep data availability at every wave (Health and Retirement Study, 2020; Sasson & Umberson, 2014). This would enable more accurate analysis of length of time since bereavement and sleep disturbance. For instance, comparisons could be made with women who remained married or were always widowed (Sasson & Umberson, 2014); or between women whose partners died from different conditions. Further, with more sleep data and greater numbers of transitions to ceasing care, comparison of sleep disturbance by reason for care cessation (widowhood, recovery, institutionalisation) could be carried out, similar to studies of caregiving and depression and life satisfaction (Gerlich & Wolbring, 2021; Kaufman et al., 2019). Such research could contribute to knowledge of the years following bereavement and the end of caregiving, as evidence is less prevalent in both areas compared to married couples or current caregivers (Corey et al., 2020; Keene & Prokos, 2008; Magan et al., 2020). Addressing other health and

wellbeing factors at the same time as sleep disturbance would provide a more nuanced picture of widowhood and care cessation.

The investigations in this thesis further our understanding of the links between caregiving and sleep disturbance, addressing important characteristics and transitions, as well as the role of partner health in the context of couples. It contributed by filling gaps in the longitudinal evidence base on the relationship of care, care duration and how partner health is related to sleep disturbance. Investigation of caregiving intensity and transitions was carried out in the English context, previously not addressed among mid- and late life adults. Limited support was found for some hypothesised relationships between caregiving characteristics that may be perceived as stressful and sleep disturbance, for instance, for longer care duration among women. Some unexpected results were also found, for instance, links with spouse care and longer hours of care among men but not women. Among women, links were found between sleep disturbance and ceasing care provision and several partner health conditions. Nevertheless, associations found were weak, 5-7% increases in the probability of sleep disturbance, and sometimes inconsistent. Therefore, evidence is not sufficiently strong to recommend specific caregiver support. Future research on links between social relationships (including caregiving) and sleep disturbance would benefit from increased frequency of sleep data collection to enable closer modelling of changes in relationships and sleep.

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Appendix A – Chapter three

Table A1: Longitudinal caregiver sleep studies (including non-caregivers or incorporating partner characteristics)

Author, date, location, and data source	Study sample and mean age	Analytical models employed	Follow up period	Caregiving measure and covariates	Sleep measure/s	Results
1. Hajek et al., 2020 Location: Germany Data: Deutscher Alterssurvey, DEAS	22,910 adults aged 40 – 97 years 64.8 years (standard deviation: 11.2)	Asymmetric fixed effects models	Four waves, 3 years apart	Transitions into and out of caregiving: “...care for regularly due to their poor state of health...” Covariates: age, marital and employment status, self-rated health, number of conditions and physical functioning score for SF-36	Responses to 3 questions analysed separately: 1. difficulty falling asleep (sleep problem = once per week or more), 2. waking up (as above) and 3. overall sleep quality (continuous 1-4, 4 bad sleep).	Men: starting to provide care = overall ↓ sleep quality and ↑ difficulty waking up. No associations with ceasing care or among women.
2. Gerlich and Wolbring, 2020 Germany German Socio-	231 caregivers starting care; 288 ceasing; 230 starting and ceasing	Random and fixed effects models; dummy impact function for transition	Sleep sub-analysis on annual waves 2008-2016	Spouse care (including household tasks) Covariates: age and dummy years after transition until 4+	(Main DV is life satisfaction) Sub-analysis on satisfaction with sleep domain	Starting care = ↓ satisfaction with sleep but NS. After 4+ years, significant Ceasing care due to recovery = NS Ceasing care due to bereavement = ↓ sleep

economic Panel Study	Mean age 69 years (sd: 11) women; 70 years (sd: 11) men	and 4+ years after				satisfaction in some years including year of transition
3. Maun et al., 2019 Location: UK Data: UK Household Longitudinal Study	2,470 adults aged 65 and over 55% of sample aged 65-74 years	Logistic regression models controlling for baseline level of problematic sleep	2 waves of sleep data, 3 years	Co-resident / non-resident / no care; hours of co-resident care per week; transitions/stability in co-resident care Controlled for age, gender, marital status, SRH, distress (in some analyses), baseline sleep	Problematic sleep defined as 2 or more problems with going to sleep, staying asleep and waking up tired	Cross-sectional analysis non-res and co-res NS; 50+ hours/week = ↑ odds of sleep problems Adjusting for baseline sleep, co-resident caregivers, co-resident 20+ hours/week and continued co-resident care = ↑ odds of sleep problems Non-res caregivers NS; starting and ceasing 20+ hours care NS
4. DePasquale et al., 2019 Location: US Data: Work, Family and Health study	1,135 women working in care homes in New England Mean age (sd) given by group,	Two-level multilevel models	3 data points, 6 months apart	Double-duty caregivers (unpaid care of older person and paid care-home work); triple-duty caregiver (unpaid care of child and older person and paid care-home	Subjective measures: sleep duration, time spent in bed, sleep quality and sleep sufficiency (similar questions to PSQI) Objective measures: wake after sleep onset and total sleep	No associations with objectively measured sleep double-duty care of older adult. Within-person change in care to an older adult = ↓ time in bed and ↓ sleep quality.

	between 34 years (8.3) and 43 years (14.2)			work) vs paid care-home work only Covariates (depending on model): age, race, hours worked, income, education, foreign-born status	time (wrist-worn accelerometer)	
5. Rowe et al, 2008 Location: US Data: Purposive sampling through dementia support group	31 caregivers; 102 non-carers aged 60 or over. 73 years (sd 7) non-caregivers 71 years (sd 8) caregivers	Mixed effects regression	Daily for 7 days	Care to someone diagnosed with dementia who experienced night-time activity Covariates: age, education, medication, depressive symptoms	Sleep diary and actigraphy records for 7 consecutive days measuring total sleep time, sleep efficiency, sleep onset latency, wake after sleep onset and sleep quality (subjectively measured only)	Caregivers ↓ objectively measured total sleep time, ↑ time to get to sleep (latency), wake after sleep onset NS Subjective measures NS for caregiving but significant associations with depressive symptoms.
6. Sacco et al, 2017 Location: Sweden Data: Swedish Longitudinal Occupational Study of Health	21,604 people in employment for cross-sectional analysis; 12,243 people in employment with at least	Mixed (random effects) regression model; fixed effects sensitivity analysis	Up to four waves of data, two years apart	Caregiving; caregiving for over and under 5 hours; transitions into, continued and out of caregiving between two years Covariates: age, age ² , gender, education, marital status, pain,	Sum of responses to four questions from the Karolinska sleep questionnaire: in past 3 months, difficulties with falling asleep, repeated awakenings, premature awakening,	Cross-sectional results: caring for 5+hours 1. ↑ sleep disturbance 2. ↑ sleep disturbance (men x caregiving) Longitudinal analysis, 1. sleep disturbance: continuous caregiving over 2 years ↑ sleep disturbance

	2 waves of data for longitudinal analysis 50 years (sd: 10)			chronic disease, SRH, depressive symptoms, hours paid work	disturbed sleep. Change in sleep from prior wave.	2. Change in sleep disturbance: ceasing caregiving ↓ sleep disturbance
7. Song et al, 2017 Location: US Data: Caregiver-Study of Osteoporotic Fractures	800 caregiving and non-caregiving women 82 years (sd: 4)	Multivariate linear regression	Two data points, 3 years apart (sleep measured once)	Caregiving status and transitions over two time points. No care; ceased care; low intensity and high intensity care (>=2 ADLs and >=6 IADLs); Covariates: age, race, ADL/IADLs, medical conditions, perceived stress (interaction)	PSQI and wake after sleep onset (72 hours actigraphy), measured at the second time point	Caregiving NS in predicting subjective sleep. High intensity caregivers with higher stress ↑ wake after sleep onset than high intensity caregivers with low stress
8. Van de Straat et al., 2020 Location: Europe Data: Survey of Health, Ageing and Retirement in	32,791 adults aged 50-84 years, excluding those permanent sick or disabled and those aged 85 and over	Random effects models (level of sleep disturbance) multinomial logistic regression model	Every 2 years, waves 1, 2, 4, 5 and 6 (wave 3 not used)	No care vs starting/ continuing/ ceasing providing informal care almost every day Covariates: age, age ² , marital and parent status, education, financial distress, living area, SRH	Single item "trouble sleeping recently?", dichotomous Y/N Change in sleep: good sleep both waves (ref); good sleep t-1, poor sleep t; poor sleep t-1, good sleep t; poor sleep both waves	Change in troubled sleep: caregiving ↑ relative risk of trouble sleeping in both waves for all transitions; starting to provide care ↑ RR of sleep problems in following wave; ceasing care ↑ risk of trouble sleeping in t, no trouble in t-1.

Europe, SHARE	Mean age wave 1: 63 years (sd 8)	(change in sleep disturbance)				Random effects, odds of trouble sleeping highest when starting caregiving and lowest on ceasing care; no interaction with work; women ↑ odds trouble sleeping on starting to care than men
9. Virtanen et al., 2021 Location: Finland Data: The Finnish Public Sector study, FPS, and the Finnish Retirement and Ageing Study, FIREA.	FPS N=24,418 (Women 81%) FIREA N=2,838 (Women 80%) FPS: 55 years (sd 4) FIREA: 62 years (sd 1)	Logistic fixed effects models and random effects models	3 waves, 2 years apart 6 waves, 1 year apart	Care provision to someone due to illness, age or disability. Excluded care to healthy own children. Covariates: age, sex, SES, obesity, smoking, alcohol use, physical activity, SRH	Four question Jenkins sleep problems scale, using each of the four questions and overall any sleep problems. Responses dichotomised so sleep problem coded when occurring 5-7 nights per week.	In the larger of the two studies, informal care provision was associated with all sleep measures in fixed effects analyses and all except difficulty falling asleep in between effects analyses. Having lower control over working time increased the odds of sleep disturbance, while having higher control over working time decreased the odds of sleep disturbance.
10. Von Kaenel et al 2012 Location: US	157 spouses (109 carers of people with Alzheimer's disease, 48	Mixed model (random effects) regression	Up to 4 measurements over 3 years	Caregiving over 3 years Ceasing caregiving due to death of spouse or institutionalisation	PSQI and 72 hours of actigraphy (total sleep time, Wake After Sleep Onset (WASO), percent sleep) measured	Caregiving NS in predicting subjective or objective change in sleep measures except among caregivers ceasing due to death of a spouse: ↑

Data: University of California, San Diego's Alzheimer's Caregiver Study	non-caregivers) 75 years (sd 6) non-caregivers 74 years (sd 8) caregivers			Care duration Covariates: age, gender, education, health problems, body mass index, alcohol, physical activity, smoker, years caregiving, role overload, depressive symptoms, biomarkers	once per year, 3 years	Wake After Sleep Onset, ↓ night-time sleep % and ↑ daytime total sleep time. Care duration NS
11. Von Kaenel et al., 2014 US Alzheimer's Caregiver Study as above	126 caregivers of pwAlz	Mixed (random effects) model	4 waves of yearly data	(Caregivers only) Care duration (controlled but no coefficient provided) Covariates: Number of problem behaviours	PSQI TST, WASO, sleep percentage	On average and within individuals, a higher number of problem behaviours = ↑ caregiver WASO and ↓ sleep quality (↑ PSQI score). All objective measures NS. Positive affect and negative affect associations

Abbreviations: OR, odds ratio; NS, not significant; RR, relative risk; sd, standard deviation; SRH, self-rated health; WASO, wake after sleep onset; TST, total sleep time; PSQI, Pittsburgh sleep quality index

Table A2: Cross sectional nationally representative caregiver sleep studies

Author, date, location and data source	Study sample and mean age	Analytical model	Caregiving measure	Sleep measure/s	Results
12. Arber and Meadows, 2011 Location: UK Data: Understanding Society (UK Household Longitudinal Study)	N=14,746 adults Sample included adults over 25 years	Logistic regression	Co-resident or non-resident caregiver Hours of care Covariates: age, marital status, education, employment, self-rated health (SRH), health limits activities	Problematic sleep, measured by two problems with getting to sleep, staying asleep and sleep quality	Non-resident caregivers: NS Co-resident caregivers: Men NS once adjusted for employment Women caregiving for <20 hrs and >100 hours per week ↑ odds of sleep problems. Caregiving 20-99 hours explained by health.
13. Blinka et al., 2022 US Reasons for geographic and racial differences in stroke study	221 caregivers and 247 matched non-caregivers Mean age 69 years (sd: 7)	Linear regression	Care for chronic illness/disability Hours per week Dementia/not Co-residence Care duration Covariates: age, race, gender, BMI, CES-D	Subjectively measured total sleep time, time in bed, sleep onset latency, wake after sleep onset and sleep efficiency	Caregivers took an average 4 mins longer to get to sleep. Among caregivers only, ↑ caregiving hours = ↑ total sleep time Co-resident + dementia care + care duration NS for all sleep DVs
14. Flood and Moen, 2015 US	N= 6,839 women, 5,113 men Sample aged 55-74	Multinomial regression of gender	Care to an adult Covariates: employment, self-	Sleep duration. 7-9 hours (reference), <7	Among women aged 64-75 years, caregiving to an adult ↑ relative risk of sleeping less

Data: American Time Use Survey		and age-stratified sample (55-64; 65-74)	rated health, volunteering, marital status, child care	hours and >9 hours	than 7 hours compared to 7-9 hours.
15. Gibson et al, 2016 Location: NZ Data: Health, Work and Retirement Survey NZ	434 caregivers and 1,747 non-caregivers Median 63 years (range: 55-72 years)	Logistic regression	Co-resident or non-resident caregivers Covariates: age, gender, New Zealand deprivation index, Maori/non-Maori	Dissatisfaction with sleep; tired all the time	No significant associations with caregiving except home caregivers significantly more tired in adjusted analyses Caregivers more likely to be Maori, in deprived area and women, all associated with sleep dissatisfaction
16. Koyanagi et al, 2018 Location: 58 countries (10 High Income Countries, 27 Medium ICs, 21 Low ICs) Data: World Health Survey	258,793 adults over 18 years Mean age 39 years (sd: 16)	Logistic regression	Caregiving to a child or adult with disabilities Number of care activities, list of five Covariates: demographics, work, disability and country dummies. Mediation by depressive symptoms and perceived stress	“Severe or extreme” problems with falling asleep, waking up frequently during the night or waking up too early in the morning in the last 30 days	Caregiving status and ↑ caregiving activities, ↑ odds of sleep problems NS ORs for over half of countries. In high income countries, age-stratified ORs: ↑ odds for carers aged 18-44 and 65+, not 45-64 Sleep, depressive symptoms and perceived stress associations largely independent from each other

			(also modelled as outcomes)		
17. Laks et al., 2016 Brazil National Health and Wellness Survey	10,664 non-caregivers, 209 caregivers Mean age: 40 years (sd: 16)	Logistic regression	Providing care to a person with dementia	Diagnosis of insomnia Covariates: age, gender, marital status, insurance, education, income, comorbidity index	Caregiving for someone with dementia ↑ odds of diagnosed insomnia
18. Leggett et al., 2018 US National Health and Aging Trends Study and National Study of Caregiving	528 co-resident caregivers of 442 people with dementia	Logistic regression	(Caregivers only) Covariates: Care recipient history of falls, ADLs, IADLs, and number of chronic medical conditions	Trouble falling back asleep on how many nights per week. (5-point scale)	Falls risk (but not ADL/IADLs and conditions) associated with increased trouble sleeping (as well as caregiver own health and emotional distress)
19. Liu et al., 2020 Location: 19 US states and Puerto Rico Data: Behavioural Risk Factor	114,496 adults aged 18+, 53% over 45 years old	Logistic regression	Over the past 30 days... care or assistance... due to a health problem or disability. Care intensity <20 hrs, 20-39 hrs, 40+ hrs per week Care duration	On average how many hours of sleep do you have? Compared <7 hours per night (short sleep) to 7+ hours	Caregiving men and women = ↑ odds of short sleep duration than non-caregivers. Among caregivers only, caring for 20+ hours per week = ↑ odds of short sleep compared to care of <20 hrs; Care for 5+ years = ↑ odds of short sleep compared to

Surveillance System, BRFSS			Covariates: age, gender, race, education, work, marital status, body mass, smoking, physical activity, chronic conditions, care recipient condition		caring <2 years. Care of 2-4 years NS. CGRs for a CR with chronic condition or cancer = ↑ odds short sleep compared to CGRs for a CR with another unspecified condition (reference group)
20. Osakwe et al., 2022 US National Health and Aging Trends Study	1,142 caregivers of people with dementia Mean age: 61 (sd: 1)	Logistic regression	Care relationship (spouse/child/other); Caregiving hours Personal care/medical care/getting around Covariates: age, gender, race, clinical conditions; care recipient age and sleep problems	Trouble falling back asleep; Frequency of sleep interrupted by caregiving Range 1-5 continuous	Caregiving to others compared to spouse care = ↓ odds of sleep interruption Higher care hours and more frequent help getting around and personal care = ↑ odds of interrupted sleep. Personal care = ↑ odds of interrupted sleep. Care recipient more frequent sleep disruption (most days) = ↑ odds of interrupted sleep and falling back asleep.
21. Polenick et al., 2018 US	104 co-resident spouse caregivers of person with dementia	Linear regression	Caregiving number of ADL tasks; emotional duties; negative caregiving	How frequently sleep interrupted by caregiving, (range 1, every night -5, never)	No care recipient health or sleep difficulties associated with caregiver sleep. Total emotional difficulties and

Sub-sample from National Health and Aging Trends Study and National Study of Caregiving	244 non-spouse caregivers		relationship quality. Partner: Sum of 8 health conditions; sleep problems		number of medical/nursing tasks ↑ sleep disturbance No significant associations in non-spouse carers
22. Secinti et al., 2022 US BRFSS	203,848 non-caregivers and caregivers of people with dementia (5,525), cancer (4,246), lung disease (1,959) and diabetes (2,853) Mean age: 48 years (0.1)	Logistic regression (5 waves of pooled data)	Care question as above. Care intensity (continuous) Care duration (continuous) Caregiver of person with dementia/ cancer/ lung disease/ diabetes Covariates: as for Lui et al above excluding smoking and activity	Sleep duration <7 hours (ref) compared to 7+ hours per night	↑ caregiving hours = ↓ odds of sleeping 7+ hours compared to non-caregivers Providing personal care = ↓ odds of sleeping 7+ hours All caregiver groups ↓ odds of sleeping 7+ hours compared to non-caregivers Care duration NS
23. Song et al., 2021 South Korea Data: Korean Community Health Survey	2,537 coresident caregivers (dementia); 8,864 non-resident caregivers and 190,278 non-caregivers Mean age non-caregivers: 53 (17)	Logistic regression	Care location: co-resident or non-resident (caregiving for person with dementia) and no care provision	Descriptive use of subscales. PSQI global score >5 outcome	Poorer sleep across the range of subscales in co-resident caregiving group; three subscales for non-resident caregivers (descriptive) Both co- and non-resident caregivers of people with

	Co-res caregivers: 60 (17); Non-res: 51 (15)		Covariates: age, gender, body mass index, SES variables, alcohol, smoking, exercise, hypertension, diabetes, SRH, perceived stress, cognitive decline and depression		dementia were more likely to report sleep disturbance than non-caregivers. Odds higher for coresident than non-resident.
24. Trivedi et al., 2014 Location: 7 US States Data: Behavioural Risk Factor Surveillance System	10,029 caregivers and 10,029 matched non-caregivers, all aged over 18 years Mean age: 55 years (sd: 15)	Propensity score matching and logistic regression	Over the past 30 days... care or assistance... due to a health problem or disability Covariates: gender (non-caregivers already matched on age, gender, marital status, race, whether a veteran, work, education and income	On average how many hours of sleep do you have? Inadequate sleep, coded as not 7-9 hrs How often fall asleep unintentionally?	Lower odds of adequate sleep (7-9 hrs on average) among caregivers compared to non-caregivers Men caregivers more likely to fall asleep unintentionally in the daytime than non-caregivers (not women)

Abbreviations: OR, odds ratio; NS, not significant; RR, relative risk; sd, standard deviation; SRH, self-rated health; WASO, wake after sleep onset; TST, total sleep time; PSQI, Pittsburgh sleep quality index

Table A3: Cross sectional purposive caregiver sleep studies including non-caregivers

Authors, date, and location	Study sample and mean age	Analytic model	Caregiving measure	Sleep measure/s	Results
25. Brummett et al, 2006 USA	175 caregivers 169 non-Caregivers 61 years carers 56 years non-carers	Structural equation model	Caregiver of a person with dementia Co-variates: age, gender, social support, negative affect	Pittsburgh Sleep Quality Index global score (PSQI), six of seven items (sleep efficiency removed)	Caregiving – sleep quality association fully mediated by negative affect (↓ negative affect among caregivers associated with ↓ sleep quality). ↓ social support another pathway from caregiving to negative affect.
26. Fonareva et al, 2011 USA	20 caregivers 20 non-caregivers 65 years (sd 7) caregivers 67 years (sd 8) non-caregivers	Linear regression	Caregiver of person with dementia Covariates: age and depressive symptoms	PSQI and objectively measured wake after sleet onset, total sleep time, sleep stages (polysomnography)	Sleep onset latency NS but shorter total sleep time (of 2 sleep stages) in caregivers compared to non-caregivers (no multivariate analysis for PSQI)
27. Fredman et al, 2014 USA	92 caregivers 137 non-caregivers 74 years (sd 8)	Linear regression	Caregiver of person with Alzheimer’s or Parkinson’s disease, assisting with ADL/IADLs Covariates: demog and SES, physical activity, medical conditions, positive affect	PSQI and two subscales (sleep quality and daytime dysfunction)	No significant difference between caregivers and non-caregivers in how positive affect and depressive symptoms were related to sleep quality and daytime dysfunction

28. Kochar et al, 2007 USA	375 caregiving women 694 matched non-caregiving women 81 years (sd: 4), range 69-95 years old	Logistic regression	Assistance provided with ADL/IADL Location and relationship of care; Dementia/not Covariates: age, IADLs, medications, depressive symptoms, CES-D 20	Trouble falling asleep, staying asleep and waking up early: often vs sometimes or never	Caregiving NS but caregiving with high CES-D ↑ odds of all 3 sleep problems. No difference by dementia diagnosis; but spouse and non-spouse care differing sleep problems; co-resident care ↑ odds of all 3 sleep problems when high CES-D High CES-D associated with sleep problems irrespective of care recipient condition.
29. Mills et al., 2009 US	81 spouse caregivers of people with Alzheimer's and 41 non-carers	Linear regression	Caregiving status for an individual with moderate/severe dementia vs low	Wake after sleep onset (WASO) and sleep efficiency from 1 night polysomnography	Men caring for a spouse with moderate/severe dementia had greater WASO than those not caring or low dementia score and women caring for a spouse with same dementia scale score
30. Simpson et al., 2015 US	59 co-resident and 21 non-resident caregivers of people with dementia	Linear regression	Caregiving location, hours, relationship Care recipient age, severity of disease and behaviours	PSQI continuous score	Care location NS Care recipient factors were not associated with sleep quality (multiple roles ↑ sleep quality)

31. Song et al., 2021 USA Regional postal survey of women's veterans	243 women veteran caregivers 1,214 women veteran non-caregivers Caregivers 54 years (sd 12.7) Non-caregivers 51 years (16.4)	Logistic regression	Regularly provide unpaid care and help with 1+ ADL Covariates: demographic, work, pain, SRH, body mass index	Continuous measure of summed items from the Severity Insomnia index and PSQI; Sleep efficiency; ICD-10 sleep disorders; a single item "did you have trouble sleeping because of stress?"	Caregivers ↑ odds of reporting sleep poor sleep due to stress. Other sleep variables NS
32. Wilcox and King, 1999 USA	90 caregiving women (descriptive comparison to non-caregivers) Mean age: 63 years (sd: 9)	Linear regression	Caregiving hours of person with dementia Night-time disruptions of care recipient	PSQI and seven sub-components	Night-time disruptions associated with poorer sleep quality, shorter sleep duration and lower sleep efficiency Caregiving hours NS (psychological distress and lower education increased disturbance)
33. Willett-Murphy et al, 2006 USA	37 women spouse carers 37 married women non-caregivers Mean age: 74 years (sd: 7)	Linear regression	Caregiving duration, time spent per day. Memory and behaviour problems checklist for care recipient	Sleep efficiency, total sleep time, waking after sleep onset, sleep disturbances	No caregiver or partner variables significantly associated with caregiver sleep efficiency

Abbreviations: CES-D 20, Center for Epidemiologic Studies Depression scale (20 item version); OR, odds ratio; NS, not significant; RR, relative risk; sd, standard deviation; SRH, self-rated health; WASO, wake after sleep onset; TST, total sleep time; PSQI, Pittsburgh sleep quality index

Table A4: Purposive studies including partner health/sleep or care duration (caregivers only or caregiving dyads)

Authors, date and location	Study sample	Analytical model	Caregiving measure and measure of partner health /sleep	Sleep measure	Results
34. Bartolomei et al., 2018 Italy	55 caregiving dyads of people with Parkinson's disease	Linear regression	Caregiver status Care recipient Parkinson's disease sleep scale (PDSS)	Medical Outcomes Scale Sleep Scale (MOS_SS) for caregivers	Patient sleep disturbance associated with caregiver sleep disturbance (covariates not noted).
35. Beaudreau et al., 2008 US	60 caregivers of people with dementia	Linear regression	Caregiver status Care recipient general cognitive status	Time in bed and sleep efficiency measured by wrist actigraphy	No association between CR cognitive status and CGR sleep. CGR depressive symptoms, SRH and age important
36. Chiu et al., 2014 China	180 people with dementia and caregivers	Multiple regression	Caregiver status Partner dementia severity; psychiatric symptoms	Chinese General Sleep disturbance scale	No association between partner psychiatric symptoms and caregiver sleep once caregiver fatigue added
37. Chen et al., 2020 US	54 patients and their caregivers	Cross-lagged panel models	Caregiver of cancer patient Partner condition: diagnosis of advanced liver-related cancer	PSQI individual components	Partial evidence of prospective bidirectional association between caregiver and patient sleep at 0-2 mths and 2-4 mths post-diagnosis
38. Cupidi et al., 2012	80 caregivers of people with:	Logistic regression	Care recipient age, disease severity,	PSQI (>5 poor sleepers)	Patient characteristics were NS associated with caregiver sleep quality. Caregiver depressive

Italy	Alzheimer's, mean age: 68 years (14) Parkinson's: 64 years (9)		symptom checklist and disease duration		symptoms and psychological quality of life associated.
39. Gibson et al., 2021 NZ	526 carers of person with dementia or cognitive impairment	Linear regression	Partner sleep problems; partner dementia severity; night-time care provision (all caregiver-reported)	Insomnia severity index (continuous scale)	Partner sleep problems and night-time provision of care were associated with caregiver sleep problems
40. Happe and Berger, 2002 Germany	106 caregivers of person with Parkinson's disease and partners	Logistic regression	Frequency – none/regularly but not daily/ daily Care recipient motor difficulties; bad sleep and age	Non-standard sleep questions: Have you had bad night-time sleep during the last week?	Daily caregiving and bad sleep and ten or more on motor difficulties scale in the person with Parkinson's associated with caregiver bad sleep
41. Lee et al., 2014 South Korea	132 caregivers of people with mild cognitive impairment or dementia	Linear regression	Care recipient behavioural symptoms	PSQI global score (insomnia inventory score and ESS predictors)	Behavioural symptoms were not associated with caregiver sleep quality
42. Lee et al., 2014 Taiwan	176 caregivers of people with cancer	Linear regression	Subjective and objective measures of caregiver burden Care recipient distress and health measures	PSQI Actigraphy measured TST, WASO, sleep duration, latency, efficiency	Caregivers had higher PSQI score when care recipient had a greater number of symptoms of distress (cancer Symptom Distress Scale)
43. Lee et al., 2021	129 caregivers of people with cancer	Cluster analysis then	Caregiving relationship, solo or	PROMIS* measures of sleep disturbance,	No care recipient characteristic associated with being in the high symptoms cluster.

US		logistic regression	team care, double-duty care Care recipient age, sex, primary disease, treatment	fatigue, depression and anxiety – two clusters (low and high symptoms)	Caregiver burden and loneliness were only significant factors.
44. McCurry et al., 2008 US	44 caregiver dyads of people with dementia	Multinomial regression	Dementia duration since diagnosis; mental state; depression; physical functioning; sleep medication	Objective data (wrist), profiles: concordant “good” couple sleep (ref); “poor” couple sleep; discordant couple sleep	Poorer scores on all patient health factors increased relative risk of both patient and caregiver having “poor” sleep compared to both having “good” sleep.
45. Okuda et al., 2019 US	500 carers of people with Alzheimer’s disease	Multiple linear regression	Sleep disorder inventory for patients	PSQI for caregivers	↑ patient sleep disturbances associated with poorer caregiver sleep
46. Otto et al., 2019 US	87 caregiver-care recipient dyads	Actor-partner interdependence model (APIM)	Partner anxiety and depression scores using Hospital Anxiety and Depression subscale scores	Sleep duration	Both actor and partner effects found of anxiety on shorter sleep duration. No association with depression subscale score
47. Pawl et al., 2013 US	133 caregivers of people with brain tumour	Linear regression	Care recipient ADL functioning (Karnofsky Performance Scale)	PSQI TST and WASO	Worse ADL functioning = ↑ WASO and ↓ TST

48. Peng et al., 2018 Taiwan	180 caregiving dyads of people with dementia	Linear regression	Caregiving hours Partner mini mental state examination; ADL score; wandering behaviour scale score and subscales	General sleep disturbance scale score	↑ eloping behaviour of the person with dementia was associated with ↑ caregiver sleep disturbance. Caregiving hours not significant.
49. Peng et al., 2019 US	43 caregivers of people with Alzheimer's disease	Linear multiple regression	Partner sleep measured by sleep disorders inventory score	PSQI and sleep hygiene index scores; actigraphy measurement of total sleep time, sleep efficiency	Pw-alz sleep disorder inventory score associated with poorer objectively measured total sleep time and sleep efficiency (but not wake time after sleep onset or subjective sleep quality) in caregiver
50. Simon et al., 2019 Spain Sub-sample interviewed from the official register of caregivers in Galicia	134 caregivers of people with dementia	Linear regression	Care duration >8 years vs ≤8 years; daily hours of care ≤12 hrs vs >12 hrs	Presence of insomnia, measured using the Diagnostic Interview in Mental Health	Longer care duration and longer hours of care associated with insomnia diagnosis
51. Simon et al., 2022 Spain	201 co-resident caregivers	Linear regression	Years of care (continuous); daily hours of care; care recipient physical or mental health	Poor sleep quality, PSQI >5	Hours and duration of caregiving variables not associated but higher caregiver burden associated with sleep quality.

As for Simon et al., 2019 above					
52. Simpson et al., 2013 US	80 caregivers of people with dementia	Linear regression	Care recipient daytime behaviours, dementia severity and behaviours	PSQI global score and subscales	Care recipient agitation and apathy decreased sleep quality score (PSQI subscale score) but not global score.
53. Zhang et al, 2014 China	300 spouse caregivers (600 non-caregivers – descriptives only)	Linear regression	Spouse mixed treatment / surgery / chemotherapy (unclear reference group)	Sleep disturbance (a subscale of Symptom checklist 90)	Spouse receiving mixed cancer treatment (radiotherapy/surgery/chemotherapy) ↑ caregiver sleep disturbance

Abbreviations: CES-D 20, Center for Epidemiologic Studies Depression scale (20 item version); CGR, caregiver; CR, care recipient; OR, odds ratio; NS, not significant; RR, relative risk; sd, standard deviation; SRH, self-rated health; WASO, wake after sleep onset; TST, total sleep time; PSQI, Pittsburgh sleep quality index

Table A5: Caregiver sleep studies during the COVID-19 pandemic

Authors, date and location	Study population	Analytical model (and waves where appropriate)	Caregiving measure and Covid-specific measures	Sleep measure	Results
54. Beach et al., 2021 US Online survey to research registry	576 caregivers and 2,933 non-caregivers	Linear regression	Care location, CR disability, relationship to CR, type of care	PROMIS short form for sleep disturbance	CGRs more sleep disturbance than non-CGRs in multivar models

			COVID cgr risk inventory		
55. Bergmann and Wagner, 2021 Europe SHARE Corona survey and Wave 8 (health prior to pandemic)	51,983 individuals (1,710 caregivers; 49,969 non-caregivers)	Multilevel logistic regression	Non-resident personal care vs not Relationship to CR; Static, less or more care Infection with Covid and access to medical treatment	Trouble sleeping recently?	Non-resident personal care NS for trouble sleeping (but signif for feeling sad and anxious)
56. Busse et al., 2022 Italy Two waves March 2020 and March 2021	85 caregivers, 50 non-caregivers Mean age: 68 years (sd: 15)	Linear regression, of T2 sleep by baseline covariates	Caregiving	PSQI	Sleep scores of caregivers and non-caregivers little different. Among caregivers, being female, older age, isolated and overwhelmed = ↑ PSQI
57. Greaney et al., 2022 US Online survey via Amazon Mechanical Turk	835 caregivers	Linear regression	Care hours; care duration and care burden Diagnosed with or live with COVID	Sleep disturbance score and sleep impairment score (PROMIS)	Caregivers of <6 mths duration more sleep disturbance than those 6-24mths Higher CBI ↑ sleep disturbance; also age, covid infection, ethnicity

58. Li et al., 2021 China Online questionnaire through geriatric society	160 caregivers of pw neurological disorders	Logistic regression	Community-level infection + media information	Duration <4 or >8 hrs Reduced sleep quality =1	9% reported reduced sleep quality. Access to positive media information ↑ sleep quality
59. Robillard et al., 2021 Canada Online survey distributed widely	5,525 individuals	Logistic regression	Family caregiving responsibilities (caring for a child or primary caregiver to pw chronic illness and disability)	Sleep profiles Clinically meaningful difference in PSQI score pre- and post-pandemic (retrospective), 3 points	Family responsibilities ↑ odds of new clinically meaningful sleep difficulties
60. Steel et al., 2022 US Sample from ongoing intervention trial	78 caregivers, 161 pw cancer Mean age 64 (10) and 65 (11)	Linear regression	COVID 23 item questionnaire	PSQI total score (caregiver and pw cancer)	Patient worry about infection with COVID19 associated with sleep; only age among caregivers
61. Yuan et al., 2022 China Telephone survey: Feb 2020 and Oct/Nov 2020	531 caregivers (Alzheimer's 54%) Mean age: 74 years (sd: 10)	Mixed model	Care recipient disease (control for age and sex)	PSQI >5 Sub-scales	Overall PSQI no change baseline to Oct. Sleep quality decreased for some groups. Sleep duration decreased for caregivers of people with Alzheimer's disease and cognitive impairment

Abbreviations: , caregiver; CR, care recipient; OR, odds ratio; NS, not significant; sd, standard deviation; PSQI, Pittsburgh sleep quality index; PROMIS, patient reported outcomes information system

Appendix B – Chapter five

B1 – Details of coding for diagnosed conditions

Coding of variables for diagnosed conditions included data from all ELSA waves due to a small problem with feed forward information discovered by the ELSA team (communication with ELSA team June-July 2021). Ten heart conditions and between nine and 11 other conditions were coded separately for each wave before being appended to a single file. For each wave, the reported diagnosed heart conditions from the previous wave (or current diagnosed heart conditions for Wave 1 and any respondent's first interview in ELSA) were used to code 1 for the condition and 0 for no diagnosis (variables *hedim*, *hediac* and *hedaw** dependent on wave). Respondents indicating a new diagnosis in the current wave were also used to code the condition as 1 (variables *hedim* and *dhedim*). Once all waves were appended, final variables for waves 4, 6 and 8 were coded. In wave 4, the diagnosed condition at any of waves 1 to 4 was coded 1 at wave 4. For some conditions, respondents were asked if they still had the condition from the previous wave. Respondents who answered "no" to still having the condition were recoded as not having the diagnosed condition if the response was consistent across subsequent years. Wave 6 data was coded in a similar way using responses from the final wave 4 variable and waves 5 and 6; and wave 8 coded using final wave 6 data and waves 7 and 8 data. A similar process was followed for other conditions such as lung disease and arthritis using the following variables, *hedib*, *hedibw*, *hedbw**, *hedbs**. All heart and other conditions were summed to code a total conditions variable, range 0-13 and several specific conditions were also included in analyses, see section 5.4.3.

B2 – Equations for random effects, within-between random effects and two-level multilevel models

Random effects regression model equation (Andres et al., 2013):

$$(Y_{it} - \theta\bar{Y}_i) = \beta_0(1 - \theta) + \beta_1(X_{it} - \theta\bar{X}_i) + \beta_2(Z_i - \theta\bar{Z}_i) + (v_i - \theta\bar{v}_i) + (e_{it} - \theta\bar{e}_i)$$

Where θ is a portion of the idiosyncratic and time-varying variance, taking account of the panel structure but allowing time invariant variables to be estimated as only a fraction of a variable's mean is subtracted (Andres et al., 2013). All other coefficients as equation 1 and 2 in Methodology section 5.4.

The within-between random effects model can be specified as below (Bell et al., 2019):

$$Y_{it} = \beta_0 + \beta_{1w}(X_{it} - \bar{X}_i) + \beta_{2b}\bar{X}_i + \beta_3Z_i + (v_i + e_{it})$$

Where β_{1w} represents the coefficient for variation within individual i for each time-varying variable X (the within effect). It is calculated by subtracting the average value for each variable, from the value for each individual at each timepoint, group de-meaning $(X_{it} - \bar{X}_i)$. β_{2b} represents the coefficient for the average of the time-varying variables X for all individuals \bar{X}_i (the between effect) (Bell et al., 2019). β_3 is the coefficient for each time invariant variable, a between effect by default, all other terms as equation 1 and 2 in Methodology section 5.4.

The two-level multilevel model with random intercept can be specified as below and is similar to the random effects model above, but with individuals nested in groups (Snijders & Bosker, 2012):

$$Y_{ij} = \gamma_{00} + \gamma_{10}X_{ij} + \beta_2Z_j + U_{0j} + R_{ij}$$

Where γ_{00} is the average group's intercept and γ_{10} is the coefficient for the variable X , U_{0j} , the variation at the level of the group and R_{ij} , the variation at the level of the

individual (Snijders & Bosker, 2012). These variance components are used to calculate, ρ , the intraclass correlation coefficient, ICC, a measure of the correlation in the outcomes of two individuals within a group or the variability in the outcome attributed to the group level²⁹. The same statistic can be calculated from a random effects model with data set to nest individuals within groups.

$$\rho(Y_{ij}, Y_{i't}) = \frac{\tau_0^2}{\tau_0^2 + \sigma^2}$$

Where $\tau_0^2 + \sigma^2 = \text{var}(U_{0j}) + \text{var}(R_{ij}) = \text{var}(Y_{ij})$.

²⁹ The ICC for a multilevel logistic regression model is calculated differently, as the residuals are assumed to be drawn from a logistic distribution with mean 0 and variance 3.29 ($\pi^2/3$), required by the use of the logit link function (Snijders & Bosker, 2012). It has a slightly different interpretation as a result.

Appendix C - Chapter six

Table C1: Item level missing at each of waves 4, 6 and 8

	Wave 4 (9,562)			Wave 6 (8,746)			Wave 8 (6,889)		
	Complete	Missing	% missing of total wave	Complete	Missing	% missing of total wave	Complete	Missing	% missing of total wave
Sleep disturbance	9,547	15	0.1	8,734	12	0.1	6,887	2	0.03
Caregiving	9,491	71	0.7	8,580	166	1.9	6,801	88	1.3
Marital status	9,560	2	0.02	8,744	2	0.02	6,886	3	0.04
Non-housing wealth	9,349	213	2.2	8,600	146	1.7	6,815	74	1.1
Limiting illness	9,554	8	0.08	8,741	5	0.06	6,888	1	0.01
Pain	9,549	13	0.1	8,738	8	0.09	6,889	0	0
Physical activity	9,554	8	0.08	8,744	2	0.02	6,888	1	0.01
Self-rated health	9,555	7	0.07	8,739	7	0.08	6,888	1	0.01
Depressive symptoms	9,433	129	1.3	8,630	116	1.3	6,822	67	1.0

Notes: of all core members who gave a full or partial interview, had a valid weight and were therefore aged 50 or over and living in England in private residential accommodation. Data source: English Longitudinal Study of Ageing, ELSA waves 4, 6 and 8. Author's own calculations

Table C2: Sleep disturbance (measured continuously) by caregiving characteristics, gender and wave

	No care	Care <20 hrs/wk	Care 20+ hrs/wk	Spouse care	Parent care	Other care	Non- resident care	Co-resident care
Women								
<u>Wave 4</u> N=5,052								
Mean sleep disturbance (se)	2.41 (0.01)	2.38 (0.06)	2.65 (0.07)	2.64 (0.08)	2.47 (0.07)	2.37 (0.09)	2.39 (0.06)	2.66 (0.07)
P value	Ref	0.7	<0.001	0.003	0.4	0.7	0.8	<0.001
<u>Wave 6</u> N=4,626								
Mean sleep disturbance (se)	2.41 (0.02)	2.40 (0.08)	2.61 (0.08)	2.67 (0.09)	2.40 (0.10)	2.37 (0.13)	2.42 (0.08)	2.60 (0.09)
P value	Ref	0.9	0.02	0.003	0.8	0.7	0.9	0.03
<u>Wave 8</u> N=3,733								
Mean sleep disturbance (se)	2.47 (0.02)	2.52 (0.09)	2.37 (0.13)	2.47 (0.02)	2.48 (0.12)	2.48 (0.13)	2.40 (0.10)	2.53 (0.12)
P value	Ref	0.6	0.4	0.9	0.9	0.5	0.4	0.6
Men								
<u>Wave 4</u> N=4,087								
Mean sleep disturbance (se)	2.10 (0.01)	2.20 (0.07)	2.17 (0.09)	2.17 (0.08)	2.20 (0.09)	2.21 (0.11)	2.22 (0.08)	2.16 (0.08)
P value	Ref	0.2	0.4	0.4	0.3	0.3	0.1	0.4
<u>Wave 6</u> N=3,704								
Mean sleep disturbance (se)	2.12 (0.02)	2.06 (0.09)	2.40 (0.11)	2.34 (0.10)	2.16 (0.13)	1.93 (0.14)	1.96 (0.10)	2.38 (0.10)
P value	Ref	0.5	0.02	0.04	0.8	0.2	0.1	0.01
<u>Wave 8</u> N=2,928								
Mean sleep disturbance (se)	2.16 (0.02)	2.40 (0.15)	2.48 (0.14)	2.38 (0.10)	2.52 (0.22)	2.43 (0.20)	2.32 (0.13)	2.53 (0.14)
P value	Ref	0.1	0.03	0.04	0.1	0.2	0.2	0.01

Notes: Weighted by relevant cross-sectional weight; p values calculated using t-tests from regression models; ELSA waves 4, 6 and 8; Author own calculations

Table C3: Characteristics by caregiving relationship and gender, wave 4

	Women, N=5,052 (55.3%)				Men, N=4,087 (44.7%)			
	No care N=4,631 (91.7%)	Other care N=113 (2.2%)	Parent/- inlaw care N=169 (3.3%)	Spouse care N=139 (2.7%)	No care N=3,843 (94.0%)	Other care N=46 (1.1%)	Parent/- inlaw care N=72 (1.8%)	Spouse care N=126 (3.1%)
Sleep disturbance	p=0.5				p=0.7			
Low/med disturbance	78.0	78.1	77.2	72.2	69.7	70.3	65.6	65.5
High disturbance	22.0	21.8	22.8	27.8	30.3	29.7	34.4	34.5
Married	P<0.001				P<0.001			
Never married/divor/sep	56.8	52.7	70.3	97.7	72.9	64.1	72.1	96.0
Widowed	18.2	29.1	22.5	1.6	17.6	29.7	26.4	3.3
	24.9	18.1	7.2	0.6	9.5	6.2	0.1	0.7
Mean age (SD)	66.7 (0.2)	64.7 (0.9)	58.2 (0.4)	64.9 (0.8)	64.8 (0.2)	63.6 (1.2)	58.4 (0.5)	68.9 (1.1)
Not in paid work	p<0.001				p<0.001			
In paid work	61.8	55.0	32.4	62.8	49.0	18.1	19.2	57.6
	38.2	45.0	67.6	37.2	51.0	81.9	80.8	42.4
Owns home	p=0.05				p=0.1			
Mortgage	62.4	64.3	57.0	65.4	59.5	53.5	59.3	62.6
Renting	18.3	20.1	31.1	16.2	24.0	23.1	33.3	17.5
	19.2	15.6	11.9	18.3	16.6	23.3	7.3	19.9
Highest wealth quintile	p=0.06				p=0.1			
Second highest	18.2	19.6	24.6	13.0	22.0	27.1	32.6	16.4
Middle quintile	19.0	23.1	22.9	18.0	21.4	16.6	25.0	16.3
Second lowest	19.9	23.2	23.9	22.2	20.0	28.8	14.7	21.6
Lowest wealth quintile	22.1	17.2	17.3	22.2	17.7	16.1	17.0	19.4
	20.8	16.9	11.4	24.6	18.9	11.4	10.7	26.3
No long-standing illness	p=0.1				p=0.09			
	45.1	47.1	52.7	45.1	47.3	51.2	57.7	41.0

Non-limiting illness	18.5	20.4	20.4	13.4	20.8	19.3	24.9	18.6
Limiting illness	36.4	32.5	26.9	41.6	31.9	29.5	17.3	40.4
	p<0.001				p=0.8			
No/weak pain	67.2	76.1	78.7	58.7	76.7	81.1	73.3	76.3
Moderate/severe pain	32.8	23.9	21.3	41.3	23.3	18.9	26.7	23.7
Moderate/vigorous activity	p<0.001				p=0.04			
Once per week	55.6	71.7	67.7	61.2	65.8	79.2	72.6	57.4
Less than once/wk	44.4	28.3	32.3	38.7	34.2	20.8	27.4	42.6
Self-rated health	p<0.001				p=0.01			
Good or better health	71.1	81.3	84.9	71.4	73.0	81.8	85.4	63.4
Fair or poor health	28.9	18.6	15.1	28.6	27.0	18.2	14.6	36.6
Depressive symptoms	p=0.05				p=0.3			
Less than 3	78.5	87.9	82.9	74.9	86.0	93.6	87.5	82.0
3+ symptoms	21.5	12.1	17.1	25.1	14.0	6.4	12.5	18.0

Notes: Weighted. ELSA wave 4; P-values calculated from design-based F statistics (categorical variables) and t-tests from regression models (age); Author's own calculations

Table C4: Characteristics by caregiving location and gender, wave 4

	Women, N=5,052 (55.3%)				Men, N=4,087 (44.7%)			
	No care N=4,631 (91.7%)	Non-resident care N=258 (5.1%)	Co-resident care N=163 (3.2%)	P value	No care N=3,843 (94.0%)	Non-resident care N=110 (2.7%)	Co-resident care N=134 (3.3%)	P value
Sleep disturbance								
Low/med disturbance	78.0	78.1	72.2		69.7	65.5	67.2	
High disturbance	22.0	21.9	27.8	0.2	30.3	34.5	32.8	0.5
Married	56.8	65.3	89.8		72.9	73.2	90.7	
Never married/divor/sep	18.2	22.5	9.1		17.6	23.4	8.6	
Widowed	24.9	12.1	1.1	<0.001	9.5	3.5	0.6	<0.001
Mean age (SD)	66.7 (0.19)	60.8 (0.49)	64.0 (0.73)		64.8 (0.17)	60.5 (0.70)	68.2 (1.03)	
Not in paid work	61.8	39.7	61.0		49.0	16.8	56.8	
In paid work	38.2	60.3	39.0	<0.001	51.0	83.2	43.2	<0.001
Owns home	62.4	59.7	64.5		59.5	57.4	62.1	
Mortgage	18.3	27.7	17.0		24.0	31.8	16.4	
Renting	19.2	12.6	18.5	0.005	16.6	10.8	21.6	0.06
Highest wealth quintile	18.2	23.9	12.7		22.0	31.2	16.9	
Second highest	19.0	23.9	17.4		21.4	22.3	16.4	
Middle quintile	19.9	22.6	24.0		19.9	21.3	20.2	
Second lowest	22.1	17.5	21.0		17.7	14.3	21.3	
Lowest wealth quintile	20.8	12.1	24.9	0.003	18.9	11.0	25.3	0.08
No long-standing illness	45.1	50.3	46.4		47.3	53.3	43.7	
Non-limiting illness	18.5	20.7	14.1		20.8	23.7	18.2	

Limiting illness	36.4	29.0	39.5	0.1	31.9	23.0	38.1	0.2
No/weak pain	67.2	79.2	59.5		76.7	78.7	74.1	
Moderate/severe pain	32.8	20.8	40.5	<0.001	23.3	21.2	25.9	0.7
Moderate/vigorous activity								
Once per week	55.6	69.5	62.0		65.8	74.0	59.5	
Less than once/wk	44.4	30.5	38.0	<0.001	34.2	26.0	40.5	0.08
Self-rated health								
Good or better health	71.1	83.5	73.5		73.0	86.7	62.6	
Fair or poor health	28.9	16.5	26.5	<0.001	27.0	13.4	37.4	<0.001
Depressive symptoms, (no sleep item)								
Less than 3	78.5	84.2	77.4		86.0	89.8	82.5	
3+ symptoms	21.5	15.8	22.6	0.1	14.0	10.2	17.5	0.3

Notes: Weighted. ELSA wave 4; P-values calculated from design-based F statistics (categorical variables) and t-tests from regression models (age) Author's own calculations

Appendix D - Chapter seven

Table D1: Means and variation in sleep disturbance (continuous measure) over waves 4-8 by gender

	Weighted means			Variation across three waves (xtsum), unweighted			
	Wave 4 N=7,198	Wave 6 N=7,803	Wave 8 N=6,305	Mean	Sd overall	Sd between	Sd within
Sleep disturbance (continuous)							
Women	2.42	2.41	2.45	2.42	0.89	0.77	0.46
Men	2.09	2.14	2.17	2.12	0.81	0.69	0.44

Data source: ELSA waves 4, 6 and 8. Author's own calculations. Means weighted by relevant cross-sectional weights. Abbreviations: sd, standard deviation

Table D2: Percentages, means and variation in covariates over waves 4-8

Variable (categorical)	Weighted percentages of sample			Variation across three waves (xttab) unweighted			
	Wave 4 N=7,189	Wave 6 N=7,803	Wave 8 N=6,305	Overall person/ waves: 21,306 % (obs)	Between variation (ever been)	Within variation (% stable for ever been)	Overall stability (average within variation)
Men	47.0	47.3	47.8	44.4	44.4	100	100
Women	53.0	52.7	52.2	55.6	55.6	100	
Married*	67.4	65.4	64.2	64.7	68.5	94.0	91.2
Sep/div/never married	18.3	20.2	21.7	19.3	21.2	90.8	
Widowed	14.3	14.4	14.1	16.0	19.9	82.0	
Highest wealth*	21.6	21.0	20.7	22.3	32.4	67.6	59.2
2 nd highest	21.3	20.6	21.3	22.2	39.5	55.5	
Middle	19.8	20.0	20.1	20.6	38.1	53.9	
2 nd lowest	18.8	19.8	20.6	19.4	34.8	56.8	
Lowest wealth	18.6	18.5	17.3	15.5	24.1	66.0	
Not in work*	51.5	56.7	61.1	62.1	77.6	79.8	75.5
In paid work	48.5	43.3	38.9	37.9	54.9	69.4	
Good or better health*	75.6	72.7	72.6	73.8	85.1	85.9	79.9
Fair or poor health	24.4	27.3	27.4	26.2	40.2	67.1	
Depressive symptoms <=2	84.0	84.1	85.2	85.0	94.3	89.7	82.4
>=3 symptoms	16.0	15.9	14.8	15.0	27.0	57.1	
No pain*	73.0	71.1	71.4	71.4	85.0	83.6	77.0

Moderate /severe pain	27.0	28.9	28.6	28.6	44.7	64.6	
No illness*	47.8	46.9	45.2	44.4	61.7	71.8	66.6
Non-limiting ill	20.5	19.2	20.6	21.2	38.2	54.3	
Limiting illness	31.7	33.9	34.2	34.4	50.2	69.5	
Moderate/vigorous activity >once per week*	64.8	63.1	63.5	64.1	82.5	77.0	71.4
Once per week or less	35.2	36.9	36.5	35.9	57.6	63.5	
	Weighted mean (se)			Variation across three waves (xtsum), unweighted			
Variable (continuous)	Wave 4	Wave 6	Wave 8	Mean	Sd overall	Sd between	Sd within
Mean age*	64.3 (0.12)	66.4 (0.15)	68.6 (0.18)	67.9 (9.5)	9.5	9.2	3.1

Notes: weighted proportions. *Variables with significant differences across waves 4, 6 and 8 (unweighted analysis), $p < 0.05$; abbreviation: sd, standard deviation; se, standard error; Data source: ELSA waves 4, 6 and 8.

Table D3 Frequency of transitions – caregiving hours and relationship of care

Variable	Frequency
Women	
No care	373
<20 hours	283
20+ hours	240
Spouse	143
Parent	196
Other	127
Men	
No care	218
<20 hours	151
20+ hours	95
Spouse	107
Parent	78
Other	51

Notes: transitions calculated manually, using lag of two waves. Transitions between waves of 1 to 0

Table D4 Comparison of coefficients from RE and FE models of caregiving hours and sleep disturbance, women

	FE coefficients	RE coefficients	b-B difference	Standard error
<20 hours care	-0.01	0.00	-0.01	0.01
20+ hours care	0.05	0.04	0.00	0.01
Age	-0.00	-0.00	0.00	0.01
Age-squared	-0.00	0.00	-0.00	0.00
Wave 6	0.01	0.01	0.00	0.02
Wave 8	0.02	0.01	0.00	0.05
Never married/sep/div	0.02	-0.01	0.02	0.03
Widowed	0.06	0.01	0.05	0.02
In paid work	0.01	-0.00	0.01	0.01
2 nd wealth	-0.00	0.01	-0.01	0.01
Middle quintile	0.00	0.02	-0.02	0.01
2 nd lowest	-0.02	0.01	-0.03	0.01
Lowest wealth	0.05	0.07	-0.03	0.02
Activity once/wk or less	0.02	0.02	-0.01	0.01
Non-limiting illness	0.00	0.02	-0.01	0.01
Limiting illness	0.02	0.04	-0.02	0.01
Pain	0.04	0.09	-0.05	0.01
Fair/poor health	0.05	0.09	-0.03	0.01
3+ depressive symptoms	0.08	0.14	-0.06	0.01

Hausman test of systematic difference between coefficients (StataCorp, 2017a)

$$Hausman\ statistic = \frac{\beta_{FE} - \beta_{RE}}{(\sigma_{FE}^2 - \sigma_{RE}^2)(\beta_{FE} - \beta_{RE})}$$

Where $\beta_{FE} - \beta_{RE}$ is the vector of coefficients from the fixed effects model, subtracted from those from the random effects model and $\sigma_{FE}^2 - \sigma_{RE}^2$ is the covariance matrix for the fixed effects model subtracted from the covariance matrix of the random effects model.

$$X^2_{(18)} = 152.4, p < 0.001$$

Table D5: Sensitivity analyses for Table 7.6, final models, constrained and continuous models, women

	Binary dependent variable (highest sex-specific tertile)			Continuous dependent variable
	Constrained	Full sample	Constrained	Full sample
	Model 1 (FE logit model, as M3, Table 7.6)	Model 2 (FE linear probability model, as M6, Table 7.6)	Model 3 (FE linear probability model, constrained)	Model 4 (FE linear model)
Care < 20 hours	0.95 (0.64 – 1.39)	0.01 (-0.04 – 0.03)	-0.01 (-0.15 – 0.12)	0.00 (-0.06 – 0.07)
20+ hours	1.47 (0.94 – 2.32)	0.05 (0.00 – 0.09)	0.13 (-0.02 – 0.29)	0.11** (0.03 – 0.20)

Notes: Models 1 and 3, N=1,172 women with 3,175 observations; N (M2 and M4): 4,499 women with 11,840 observations; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); LPM and linear FE model estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, waves 4, 6 and 8. Author's own calculations.

Table D6: Sensitivity analyses for Table 7.7, final models, constrained and continuous models, men

	Binary dependent variable (highest sex-specific tertile)			Continuous dependent variable
	Constrained	Full sample	Constrained	Full sample
	Model 1 (FE logit model, as M3, Table 7.7)	Model 3 (FE linear probability model, as M6, Table 7.7)	Model 3 (FE linear probability model, constrained)	Model 4 (FE linear model)
Care < 20 hours	1.41 (0.87 – 2.29)	0.03 (-0.03 – 0.09)	0.11 (-0.06 – 0.29)	0.03 (-0.05 – 0.12)
20+ hours	1.83* (1.06 – 3.15)	0.07* (0.00 – 0.14)	0.20* (0.03 – 0.37)	0.09 (-0.03 – 0.21)

Notes: N (M1 and M2): 1,194 men with 3,249 observations; N (M3 and M4): 3,590 men with 9,466 observations; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); LPM and linear FE model estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, waves 4, 6 and 8. Author's own calculations.

Table D7: Sensitivity analyses for Table 7.8, final models, constrained and continuous models, women

	Binary dependent variable (highest sex-specific tertile)			Continuous dependent variable
	Constrained	Full sample	Constrained	Full sample
	Model 1 (FE logit model, as M3 Table 7.8)	Model 2 (FE linear probability model, as M6 Table 7.8)	Model 3 (FE linear probability model, constrained)	Model 4 (FE linear model)
Other care	0.84 (0.47 – 1.49)	-0.02 (-0.07 – 0.04)	-0.06 (-0.25 – 0.14)	-0.04 (-0.14 – 0.06)
Parent care	1.37 (0.82 – 2.27)	0.03 (-0.02 – 0.08)	0.11 (-0.07 – 0.29)	0.06 (-0.02 – 0.14)
Spouse care	1.20 (0.73 – 1.97)	0.02 (-0.03 – 0.08)	0.07 (-0.11 – 0.24)	0.10* (0.00 – 0.20)

Notes: N (M1 and 3): 1,172 women with 3,175 observations; N (M2 and 4): 4,499 women with 11,840 observations; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); LPM and linear FE model estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: ELSA, waves 4, 6 and 8. Author's own calculations.

Table D8: Sensitivity analyses for Table 7.9, final models, constrained and continuous models, men

	Binary dependent variable (highest sex-specific tertile)			Continuous dependent variable
	Constrained	Full sample	Constrained	Full sample
	Model 1 (FE logit model, as M3 Table 7.9)	Model 2 (FE linear probability model as M6 Table 7.9)	Model 3 (FE linear probability model, constrained)	Model 4 (FE linear model)
Other care	1.27 (0.57 – 2.84)	0.01 (-0.11 – 0.12)	0.07 (-0.23 – 0.36)	-0.05 (-0.21 – 0.11)
Parent care	1.59 (0.83 – 3.01)	0.06 (-0.03 – 0.14)	0.16 (-0.07 – 0.39)	0.04 (-0.07 – 0.16)
Spouse care	1.75* (1.01 – 3.03)	0.06 (-0.01 – 0.12)	0.18* (0.01 – 0.36)	0.11* (0.00 – 0.21)

Notes: N (M1 and 3): 1,194 men with 3,249 observations; N (M2 and 4): 3,590 men with 9,466 observations; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); LPM and linear FE model estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001; Data source: ELSA, waves 4, 6 and 8. Author's own calculations.

Table D9 Sensitivity analyses for Tables 7.6-7.9, using imputed datasets for final model in each table, FE LPMs, caregiving hours and relationship, women and men

	Sleep disturbance (highest sex-specific tertile)			
	Women		Men	
	Complete cases	Imputed data	Complete cases	Imputed data
Caregiving hours	(FE LPM as M6 Table 7.6)		(FE LPM as M6 Table 7.7)	
Care<20 hrs/wk	0.01 (-0.04 – 0.03)	-0.02 (-0.05 – 0.02)	0.03 (-0.03 – 0.09)	0.03 (-0.03 – 0.08)
20+ hours	0.05 (0.00 – 0.09)	0.05* (0.00 – 0.09)	0.07* (0.00 – 0.14)	0.06 (-0.00 – 0.13)
Caregiving relationship	(FE LPM as M6 Table 7.8)		(FE LPM as M6 Table 7.9)	
Other care	-0.02 (-0.07 – 0.04)	-0.03 (-0.09 – 0.02)	0.01 (-0.11 – 0.12)	-0.01 (-0.13 – 0.10)
Parent care	0.03 (-0.02 – 0.08)	0.02 (-0.02 – 0.07)	0.06 (-0.03 – 0.14)	0.06 (-0.02 – 0.13)
Spouse care	0.02 (-0.03 – 0.08)	0.03 (-0.02 – 0.08)	0.06 (-0.01 – 0.12)	0.05 (-0.01 – 0.12)

Notes: N Model 1 complete cases 4,499 women (11,840 observations), Model 2 imputed data 4,706 women (12,582 observations); Model 3 complete cases 3,590 men (9,466 observations), Model 4 imputed data 3,729 men (9,952 observations); Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); Estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001; Data source: ELSA, waves 4, 6 and 8. Author's own calculations.

Appendix E - Chapter eight

Table E1 Comparison of coefficients from RE and FE models of caregiving transitions and sleep disturbance, women

	FE coefficients	RE coefficients	b-B difference	Standard error
Started care	0.01	0.02	-0.01	0.01
Continued care	0.02	0.03	-0.01	0.02
Ceased care	0.07	0.07	-0.00	0.01
Age	-0.02	-0.01	-0.01	0.01
Age-squared	0.00	0.00	0.00	0.00
Wave 6	0.04	0.02	0.03	0.02
Wave 8	0.07	-0.01	0.04	0.03
Never married/sep/div	0.03	-0.01	0.10	0.06
Widowed	0.04	0.00	0.04	0.02
In paid work	0.01	-0.00	0.01	0.01
2 nd wealth	0.01	0.01	-0.00	0.01
Middle quintile	-0.01	0.01	-0.02	0.01
2 nd lowest	-0.01	0.01	-0.02	0.02
Lowest wealth	0.04	0.06	-0.02	0.02
Activity once/wk or less	0.01	0.01	-0.01	0.01
Non-limiting illness	0.01	0.02	-0.01	0.01
Limiting illness	0.02	0.04	-0.02	0.01
Pain	0.03	0.07	-0.04	0.01
Fair/poor health	0.05	0.08	-0.03	0.01
3+ depressive symptoms	0.08	0.14	-0.06	0.01

Hausman test of systematic difference between coefficients (StataCorp, 2017a)

$$Hausman\ statistic = \frac{\beta_{FE} - \beta_{RE}}{(\sigma_{FE}^2 - \sigma_{RE}^2)(\beta_{FE} - \beta_{RE})}$$

Where $\beta_{FE} - \beta_{RE}$ is the vector of coefficients from the fixed effects model, subtracted from those from the random effects model and $\sigma_{FE}^2 - \sigma_{RE}^2$ is the covariance matrix for the fixed effects model subtracted from the covariance matrix of the random effects model.

$$X^2_{(19)} = 128.6, p < 0.001$$

Table E2 Sensitivity analyses for Table 8.6, controlling for respondent ADL difficulties and diagnosed conditions, women

	RE LPMs, β coefficients		FE LPMs, β coefficients	
	Final Model as M6 in Table 8.6	Final Model plus ADLs and total conditions	Final Model as M6 in Table 8.6	Final Model plus ADLs and total conditions
Binary sleep disturbance				
Start 20+hr care	0.02 (-0.03 – 0.07)	0.02 (-0.03 – 0.07)	0.01 (-0.05 – 0.08)	0.01 (-0.05 – 0.08)
Continued care	0.03 (-0.05 – 0.11)	0.03 (-0.05 – 0.11)	0.02 (-0.08 – 0.11)	0.02 (-0.08 – 0.11)
Cease 20+hr care	0.07* (0.01 – 0.13)	0.07* (0.01 – 0.13)	0.07* (0.01 – 0.13)	0.07* (0.01 – 0.13)
ADLs		0.01* (0.00 – 0.02)		0.01 (-0.01 – 0.02)
Total conditions		0.01*** (0.01 – 0.02)		-0.00 (-0.01 – 0.01)

Notes: 3,768 women with 9,476 observations; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$; Estimated with robust standard errors; unweighted. Data source: English Longitudinal Study of Ageing, waves 3, 4, 5, 6, 7 and 8. Author's own calculations.

Table E3 Sensitivity analysis for Table 8.6, measuring sleep disturbance as continuous, women

	RE linear models, β coefficients			FE linear models, β coefficients		
	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, health excl depressive symp)	Model 3 (M2 + depressive symptoms)	Model 4 (covariates as M1)	Model 5 (covariates as M2)	Model 6 (covariates as M3)
Continuous sleep disturbance						
Start 20+hr care	0.09 (-0.01 – 0.20)	0.09 (-0.02 – 0.20)	0.07 (-0.04 – 0.18)	0.08 (-0.04 – 0.20)	0.07 (-0.05 – 0.19)	0.06 (-0.06 – 0.18)
Continued care	0.19** (0.05 – 0.33)	0.18* (0.04 – 0.31)	0.15* (0.01 – 0.28)	0.15 (-0.00 – 0.31)	0.15 (-0.01 – 0.30)	0.12 (-0.04 – 0.28)
Cease 20+hr care	0.22*** (0.12 – 0.32)	0.20*** (0.10 – 0.30)	0.17*** (0.08 – 0.27)	0.19** (0.08 – 0.30)	0.18** (0.07 – 0.29)	0.16** (0.05 – 0.27)

Notes: 3,768 women with 9,476 observations; Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); * p<0.05, ** p<0.01, *** p<0.001; Estimated with robust standard errors; unweighted. Data source: English Longitudinal Study of Ageing, waves 3, 4, 5, 6, 7 and 8. Author's own calculations.

Table E4 Sensitivity analysis for Table 8.7, measuring change in sleep disturbance as continuous, first difference models, women

	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, health excl depressive symp)	Model 3 (M2 + depressive symptoms)
Start 20+hr care	-0.02 (-0.17 – 0.12)	-0.03 (-0.17 – 0.12)	-0.03 (-0.18 – 0.11)
Continued care	-0.03 (-0.24 – 0.19)	-0.02 (-0.24 – 0.19)	-0.03 (-0.25 – 0.19)
Cease 20+hr care	0.13 (-0.02 – 0.28)	0.13 (-0.02 – 0.27)	0.12 (-0.03 – 0.27)

Notes: 3,768 women with 6,422 observations; Adjusted for covariates as per Table 8.7, chapter 8. * p<0.05, ** p<0.01, *** p<0.001; Estimated with robust standard errors; unweighted. Data source: English Longitudinal Study of Ageing, waves 3, 4, 5, 6, 7 and 8. Author's own calculations.

Table E5 Sensitivity analysis for Table 8.8, measuring sleep disturbance as continuous, men

	RE linear, β coefficients			FE linear, β coefficients		
	Model 1 (care + age, age2, marital status, wave)	Model 2 (M1 + SES, health excl depressive symp)	Model 3 (M2 + depressive symptoms)	Model 4 (covariates as M1)	Model 5 (covariates as M2)	Model 6 (covariates as M3)
Continuous sleep disturbance						
Start 20+hr care	0.13* (0.01 – 0.25)	0.09 (-0.03 – 0.21)	0.08 (-0.03 – 0.19)	0.09 (-0.04 – 0.22)	0.08 (-0.05 – 0.21)	0.08 (-0.04 – 0.21)
Continued care	0.13 (-0.06 – 0.32)	0.09 (-0.09 – 0.27)	0.09 (-0.09 – 0.27)	0.08 (-0.16 – 0.32)	0.08 (-0.16 – 0.31)	0.19 (-0.14 – 0.33)
Cease 20+hr care	0.08 (-0.05 – 0.22)	0.04 (-0.09 – 0.17)	0.03 (-0.10 – 0.16)	0.06 (-0.10 – 0.22)	0.05 (-0.11 – 0.21)	0.05 (-0.11 – 0.21)

Notes: 3,003 men with 7,571 observations. Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); estimated with robust standard errors; unweighted.

* p<0.05, ** p<0.01, *** p<0.001. Data source: English Longitudinal Study of Ageing, waves 3, 4, 5, 6, 7 and 8. Author’s own calculations.

Table E6 Sensitivity analyses for Tables 8.6 and 8.8, using imputed datasets for final LPMs, caregiving transitions, women and men

	Sleep disturbance (highest sex-specific tertile)			
	Women Complete cases	Imputed data	Men Complete cases	Imputed data
Caregiving transitions				
Start 20+hr care	0.01 (-0.05 – 0.08)	0.05* (0.00 – 0.11)	0.07 (-0.02 – 0.16)	0.07 (-0.01 – 0.15)
Continued care	0.02 (-0.08 – 0.11)	0.06 (-0.03 – 0.14)	0.05 (-0.09 – 0.19)	0.06 (-0.07 – 0.18)
Cease 20+hr care	0.07* (0.01 – 0.13)	0.05 (-0.01 – 0.10)	0.05 (-0.05 – 0.14)	0.02 (-0.07 – 0.10)
Widowed	0.04 (-0.01 – 0.10)	0.05* (0.01 – 0.10)	0.05 (-0.04 – 0.15)	0.06 (-0.01 – 0.14)

Notes: N Model 1 complete cases 3,768 women (9,476 observations), Model 2 imputed data 4,706 women (12,582 observations); Model 3 complete cases 3,003 men (7,571 observations), Model 4 imputed data 3,729 men (9,952 observations). Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health and depressive symptoms (CES-D adapted, excluding sleep item); estimated with robust standard errors; unweighted; * p<0.05, ** p<0.01, *** p<0.001. Data source: English Longitudinal Study of Ageing, waves 3, 4, 5, 6, 7 and 8. Author’s own calculations.

Table E7 Sensitivity analysis for Table 8.9, sleep disturbance measured continuously by care duration, women and men, random effects LPMs

	Women	Men
	Model 1 (fully adjusted)	Model 2 (fully adjusted)
1 wave care	0.05 (-0.03 – 0.13)	0.02 (-0.07 – 0.11)
2+ waves care	0.23*** (0.11 – 0.35)	0.06 (-0.07 – 0.19)

Notes: Model 1 N: 3,768 women, Model 2 N: 3,003 men; Adjusted for covariates as per Table 8.9, chapter 8; * p<0.05, ** p<0.01, *** p<0.001; Estimated with robust standard errors; unweighted. Data source: ELSA waves 3, 4, 5, 6, 7 and 8. Author's own calculations.

Table E8 Relative risk of providing care by duration, baseline observation

	Women		Men	
	1 wave care	2+ waves care	1 wave care	2+ waves care
Age	1.00 (0.98 – 1.02)	0.98 (0.95 – 1.00)	1.00 (0.98 – 1.03)	1.02 (0.99 – 1.06)
Sep/div/single	0.59** (0.42 – 0.84)	0.42** (0.25 – 0.71)	0.66 (0.40 – 1.08)	0.49* (0.25 – 0.96)
Widowed	0.42*** (0.28 – 0.65)	0.25*** (0.12 – 0.50)	0.58 (0.28 – 1.21)	0.00*** (0.00 – 0.00)
In paid work	0.93 (0.69 – 1.25)	0.58** (0.38 – 0.87)	0.64* (0.43 – 0.94)	0.48* (0.27 – 0.84)
2 nd highest wealth	1.23 (0.84 – 1.79)	1.65 (0.97 – 2.82)	0.93 (0.59 – 1.47)	0.90 (0.44 – 1.87)
Middle	1.29 (0.88 – 1.90)	2.06** (1.21 – 3.50)	1.16 (0.73 – 1.84)	1.66 (0.87 – 3.17)
2 nd lowest	1.35 (0.90 – 2.02)	1.82* (1.01 – 3.27)	1.21 (0.73 – 2.01)	2.18 (1.10 – 4.31)
Lowest	1.74 (1.16 – 2.62)	2.61** (1.46 – 4.66)	1.06 (0.59 – 1.92)	2.20* (1.07 – 4.50)
Fair/poor SRH	0.77 (0.57 – 1.04)	0.87 (0.58 – 1.31)	0.94 (0.63 – 1.40)	1.34 (0.82 – 2.20)

Notes: N: 3,768 women; 3,003 men; Reference groups married; retired/out of work; highest non-housing wealth quintile; good or better self-rated health; * p<0.05, ** p<0.01, *** p<0.001; Estimated with robust standard errors; unweighted. Data source: ELSA waves 3, 4, 5, 6, 7 and 8; baseline observation from wave 4 or 6. Author's own calculations.

Appendix F – Chapter nine

Table F1 Frequency of transitions for co-resident caregiving and partner health

Variable	Women	Men
	Frequency	Frequency
Co-resident	245	199
Partner neurological	86	54
Partner cancer	230	173
Partner heart condition	205	122
Partner lung disease	103	49
Partner arthritis	294	395

Notes: transitions calculated manually, using a lag of two waves. Transitions counted as 0 to 1 and 1 to 0 (Most disease transitions are 0 to 1, diagnosis, except for some diseases, for example cancer. No transitions 1 to 0 for neurological disease and lung disease); author's own calculations

Table F2 Sensitivity analyses for Tables 9.7 and 9.8 using imputed datasets for final LPMs, co-resident care and partner health, women and men

	Sleep disturbance (highest sex-specific tertile)			
	Women Complete cases	Imputed data	Men Complete cases	Imputed data
Co-resident care	0.03 (-0.03 – 0.09)	0.02 (-0.03 – 0.07)	0.03 (-0.03 – 0.09)	0.03 (-0.03 – 0.09)
Partner neurological diagnosis	0.15** (0.06 – 0.24)	0.12* (0.01 – 0.22)	0.04 (-0.09 – 0.17)	0.08 (-0.02 – 0.19)
Partner cancer diagnosis	0.05 (-0.02 – 0.11)	0.02 (-0.04 – 0.08)	0.00 (-0.08 – 0.10)	0.03 (-0.03 – 0.09)
Partner heart condition diagnosis	0.03 (-0.02 – 0.08)	0.01 (-0.05 – 0.07)	0.00 (-0.08 – 0.08)	0.01 (-0.06 – 0.09)
Partner lung disease	0.02 (-0.07 – 0.10)	0.01 (-0.07 – 0.10)	-0.08 (-0.21 – 0.05)	-0.04 (-0.15 – 0.07)
Partner arthritis	-0.02 (-0.07 – 0.03)	-0.02 (-0.06 – 0.03)	-0.02 (-0.07 – 0.03)	-0.02 (-0.07 – 0.02)
Partner total conditions (n)	-0.00 (-0.02 – 0.01)	-0.00 (-0.01 – 0.01)	-0.00 (-0.02 – 0.02)	-0.01 (-0.02 – 0.01)
Partner ADL difficulty (n)	-0.00 (-0.02 – 0.02)	-0.00 (-0.02 – 0.01)	0.01 (-0.02 – 0.03)	0.00 (-0.02 – 0.02)

Notes: N Model 1 complete cases 2,406 women (6,225 observations), Model 2 imputed data 3,589 women (10,767 observations); Model 3 complete cases 2,384 men (6,236 observations), Model 4 imputed data 3,488 men (10,464 observations); Adjusted for age, wave, marital status, work, non-housing wealth, physical activity, limiting illness, pain, self-rated health, depressive symptoms (CES-D adapted, excluding sleep item), other care, tenure and presence of children in the household.